Palliative care needs of patients with advanced COPD: an exploration of illness experiences
Habraken, J.M.

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An exploration of illness experiences

Jolanda Habraken
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Thesis, Academic Medical Center – University of Amsterdam


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Palliative care needs of patients with advanced COPD

An exploration of illness experiences

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. D.C. van den Boom
ten overstaan van een door het college voor promoties
ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit
op woensdag 18 november 2009, te 14.00 uur

door

Johanna Maria Habraken

geboren te Schijndel
Promotiecommissie

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                Prof. dr. M.A.G. Sprangers

Faculteit der Geneeskunde
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Toen ik in het kader van dit onderzoeksproject op bezoek was bij een patiënt met COPD liet ze me dit gedicht lezen. Ze had het niet zelf geschreven, maar uitgeknipt uit een tijdschrift. Ze vertelde dat het gedicht haar had geraakt omdat ze zichzelf erin herkende. Het bracht precies onder woorden hoe het voor haar voelde om te leven met de ziekte COPD. Later merkte ik dat dit gedicht ook bij andere patiënten herkenning en troost oproept. Het gedicht wordt dan ook onderling uitgewisseld. Omdat in dit proefschrift het perspectief van de COPD patiënt centraal staat, laat ik het beginnen met dit persoonlijke gedicht.
COPD

Een ziekte met een naam, maar zonder gezicht
Van buiten niet te zien wat het van binnen heeft aangericht
De vermoeidheid, de wanhoop, het verdriet en de pijn
   Worden niet begrepen in een wereld....
   waar alles te zien moet zijn
Ik lach doe vrolijk en niet altijd even oprecht
Het sloopt me van binnen, het is een lang en eenzaam gevecht
Ik ben niet meer wie ik ooit was, ik kan niet meer wat ik ooit kon
Maar ook voor mij schijnt nog steeds de warme levenszon
Ik heb familie en vrienden, zij kennen mijn enige wens:
   Zij luisteren en beschouwen mij niet als een zieke....
   maar als mens.

_Geschreven door Theo Fritschy,
overleden op 2 januari 2005
aan de gevolgen van COPD_
Chapter 1

*General introduction*
Death has always been an unavoidable part of living. The major causes of death in developed European countries have shifted from predominantly infectious diseases towards more degenerative diseases such as cancer and cardiovascular disease\(^1\). Also, demographic changes and advances in hygiene and medicine have led to ageing of the population. As a result of these developments, sudden death has become less common. Towards the end of life, most people in developed countries acquire a serious progressive illness that increasingly interferes with their usual activities until death\(^2\). One of those progressive illnesses is Chronic Obstructive Pulmonary Disease (COPD). This thesis presents a series of studies about illness experiences of patients with advanced COPD. This introduction provides the necessary background information about palliative care, COPD, and different illness trajectories at the end of life. This chapter will end with the aim, research questions and outline of the thesis.

**Palliative care**

Palliative care originated as end-of-life care in the 1960s. At that time, it focused on providing symptom control and psychosocial and family support during the terminal phase of a life-limiting disease. Since then, its meaning and scope of practice have expanded far beyond its roots\(^3\). In the early 1980’s, the World Health Organisation (WHO) Cancer Unit began the development of a global initiative to advocate for pain relief and opioid availability at the end of life. Since then, WHO has broadened its approach to palliative care. There is now wide recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness. The physical, emotional, and spiritual needs of the patient are all considered important concerns in palliative care\(^4\). The most recent WHO definition of palliative care dates from 2002: “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

\(^{1}\)WHO, 2018
\(^{2}\)WHO, 2018
\(^{3}\)WHO, 2018
\(^{4}\)WHO, 2018
Following the same WHO definition, palliative care contains the following elements:

Palliative care...
- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Chronic Obstructive Pulmonary Disease (COPD)
COPD is a chronic, potentially fatal progressive condition of the lungs. The American Thoracic Society (ATS) and the European Respiratory Society (ERS) maintain a slightly different definition of COPD from that of the Global Initiative for Chronic Obstructive Lung Disease (GOLD)\(^5\)-7. GOLD has defined COPD in the following way: “COPD is a preventable and treatable disease with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases”\(^7\). Both this definition by GOLD, as well as the ATS definition points to the preventability and treatability of COPD, in which airflow limitation is usually progressive and not fully reversible and mention systemic or extrapulmonary elements, along with the role of exposure to noxious particles or gases\(^5\). Cigarette smoking is the most commonly encountered risk factor for COPD worldwide, although in many countries, air pollution resulting from the burning of wood and other biomass fuels has also been identified as a COPD risk factor. Once developed, COPD and its comorbidities cannot be cured and thus
must be treated continuously to reduce symptoms, improve quality of life, reduce exacerbations, and possibly reduce mortality\textsuperscript{7}.

**Epidemiology**

COPD is a serious health problem. According to the World Health Organisation, COPD ranked fourth in leading causes of death globally in 2004 (3 million deaths in total, 5.1 percent of total deaths worldwide). COPD is predicted to be the third leading cause of death globally in the year 2030\textsuperscript{8}. COPD is also associated with a substantial economic burden. Most direct costs are associated with hospitalisation (usually due to exacerbations). COPD-related costs therefore increase markedly with severity based on FEV\textsubscript{1}\textsuperscript{5,9,10}.

In the Netherlands, the prevalence of COPD based on data from general practice registers was estimated to be 176.500 men and 139.900 women (22,0 per 1.000 men and 17,1 per 1.000 women) in the year 2003\textsuperscript{11}. Based on the same general practice registers data, 17.200 men and 16.400 women are estimated to be newly diagnosed yearly (2,1 per 1.000 men and 2,0 per 1.000 women). In 2004 3.381 men and 2.281 women died from COPD (42,0 per 100.000 men and 27,7 per 100.000 women). The life expectancy of men with COPD is on average 8 years shorter than that of men without COPD (including 3 years of healthy life). Women live on average 10.5 years shorter than women without COPD (including 4 years of healthy life)\textsuperscript{12}.

**Illness trajectories at the end of life**

Recent studies have described that different illness trajectories at the end of life are characterised by their own typical patterns of functional decline\textsuperscript{2,13,14}. These differences between trajectories may be important for the provision of palliative care in varying populations. Besides sudden death, three distinct trajectories are identified\textsuperscript{2}:

*Short period of evident decline, typically cancer (Figure 1.a.)*

This trajectory describes a reasonably predictable decline in physical health over a period of weeks, months, or years. This trajectory is mostly followed by cancer patients.
**Prolonged dwindling (Figure 1.b.)**
This trajectory is followed by people who die at an older age of either brain failure or generalized frailty of multiple body systems. This trajectory describes progressive disability from an already low baseline of cognitive or physical functioning.

**Long term limitations with intermittent serious episodes (Figure 1.c.)**
Patients who follow this trajectory are usually ill for many months or years with occasional acute, often severe, exacerbations. Each exacerbation may result in death, and although the patient usually survives many such episodes, a gradual deterioration in health and functional status is typical. This trajectory is typically followed by patients with end-stage heart failure and COPD.

**Figure 1.a. Typical illness trajectory for cancer patients**

![Diagram of cancer trajectory]

**Figure 1.b. Typical illness trajectory for older frail patients**

![Diagram of frailty trajectory]
These three illness trajectories each follow their own typical pattern of functional decline. Figure 1.c. is mostly associated with the functional decline of patients in the end-stage of COPD. This illness trajectory is very different from that of cancer and frailty at the end of life. It is therefore expected that also care needs and demands of COPD patients will differ from those of cancer patients with advanced disease; the more traditional recipients of palliative care. The research described in this thesis set out to explore problems, needs and preferences of COPD patients with advanced disease.

Figure 1.c. Typical illness trajectory for patients with end-stage heart and lung failure

[Figure 1.a – 1.c.: Adapted from Murray et al. 2005^2]

COPD and palliative care
COPD is thus acknowledged as a serious health problem with a considerable disease burden. While it is recognised that COPD patients have a shorter life expectancy than their healthy counterparts, it is still difficult to determine when exactly a COPD patient is likely to die. This is due to the highly unpredictable disease trajectory (Fig 1.c.). This trajectory is characterised by long term limitations with intermittent serious episodes. Patients are usually severely impaired for a long period of time with occasional acute exacerbations. Although these exacerbations are severe and may result in death, patients usually survive many such episodes^5. This means that the last phase of COPD may be long and indistinct, and makes the exact timing of death problematic. Unsurprisingly, prognoses for individual patients with COPD are described to be inaccurate^15,16. Therefore, the death of a COPD patient often feels sudden and unexpected for family members^17. Studies have not yet provided a clear definition of the end-stage in COPD. All major international guidelines
nowadays adopt the GOLD classification of disease severity, based on spirometric values (Table 1.1).

<table>
<thead>
<tr>
<th>GOLD-stage</th>
<th>FEV₁ / FVC</th>
<th>FEV₁ (% of predicted value)</th>
<th>Frequency distribution in the Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage I: Mild</td>
<td>&lt; 0.70</td>
<td>&gt; 80</td>
<td>28 %</td>
</tr>
<tr>
<td>Stage II: Moderate</td>
<td>&lt; 0.70</td>
<td>50 – 80</td>
<td>54 %</td>
</tr>
<tr>
<td>Stage III: Severe</td>
<td>&lt; 0.70</td>
<td>30 – 50</td>
<td>15 %</td>
</tr>
<tr>
<td>Stage IV: Very severe</td>
<td>&lt; 0.70</td>
<td>&lt; 30 (or &lt; 50 and chronic respiratory failure)</td>
<td>3 %</td>
</tr>
</tbody>
</table>

FEV₁: forced expiratory volume in one second; FVC: forced vital capacity; respiratory failure: arterial partial pressure of oxygen (PaO₂) less than 8.0 kPa (60 mm Hg) with or without arterial partial pressure of CO₂ (PaCO₂) greater than 6.7 kPa (50 mm Hg) while breathing air at sea level.

Although it is now widely recognised that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness⁴, the unpredictable disease trajectory of COPD poses a challenge for the provision of high quality palliative care in this group of patients. Nonetheless, the sparse literature on end-stage COPD has shown that patients with advanced COPD may benefit from the provision of the palliative care approach²⁰,²¹ because they suffer from poor symptom control,²² especially breathlessness,¹⁷,²⁰,²³,²⁴,²⁵ anxiety¹⁷,²⁵,²⁶ and depression¹⁷,²⁵,²⁷ which often leads to social isolation,²⁰ increased dependency on others²⁸ and poor quality of life.²⁹ Despite the wider focus towards palliative care for other, non-malignant illnesses as described in the latest WHO definition⁴, palliative care has historically focused on cancer disease trajectories, and specialised services for end-stage COPD patients are still in a developing stage¹⁶,³⁰,³¹. Several studies have shown that patients in the end-stage of COPD do not have similar access to specific palliative care services when compared to patients suffering from advanced lung cancer²³,²⁹,³².
Study aim and research questions

In summary, COPD is a major health problem which represents a substantial economic and social disease burden, especially in advanced disease when exacerbations become frequent and severe. COPD also causes thousands of patients to die each year in the Netherlands. Still, at the same time, the provision of high quality palliative care to these patients is problematic. Little is known about the problems and demands for care in patients with end-stage COPD. This situation was the starting point of this research. The central aim of the study was to explore and better understand the problems, needs and preferences of patients with end-stage COPD. From this patient perspective, recommendations for improving palliative care provision will be drawn. The central aim of the study was operationalised by formulating the following research questions:

1. What is known about health care needs in end-stage COPD? What are specific areas where knowledge about needs is still lacking?
2. How does the quality of life of end-stage COPD patients compare to that of end-stage lung cancer patients?
3. How does the quality of life and functional status change over time in end-stage COPD patients?
4. How do patients with end-stage COPD express their health care needs?
5. To what extent can a better understanding of the end-stage in COPD be used to improve palliative care provision?

Study design

To answer these research questions, a mixed-methods design was adopted using both quantitative and qualitative research methods.\(^{33}\) GOLD stage IV COPD patients were identified from medical records of outpatient clinics of four participating hospitals and one centre specialising in asthma and COPD. Patients completed a self-administered questionnaire every 3 months over a period of one year or less if patients were unable to continue to participate due to increasing disease severity or death. A subgroup of patients was invited for an in-depth interview about their illness experiences. The sampling of this subgroup was done purposefully to ensure that a wide variety of patients’ experiences was recorded. A few patients were interviewed twice because the first interview did not cover all topics from the topic list, or because something changed in the patient’s
situation. Data gathered by both research methods were used as data-triangulation and were integrated in the interpretation phase of this study.

Outline of the thesis

Chapter 2 presents a structured review of the literature on health care needs in end-stage COPD patients. In this chapter an overview is given on what is already known about health care needs in end-stage COPD and in which specific areas knowledge is still lacking. Chapter 3 presents a comparison of health-related quality of life of end-stage COPD patients with more traditional recipients of palliative care: end-stage lung cancer patients. In chapter 4, results from the prospective longitudinal study are presented. This chapter will describe the changes in health-related quality of life and functional status in end-stage COPD patients during one year. Results from the qualitative part of the study are presented in chapters 5 and 6. In chapter 5, the phenomenon that end-stage COPD patients do not actively express a wish for help, despite their problems in daily life, is described and explained. Chapter 6 provides recommendations for the improvement of palliative care provision for end-stage COPD patients. In the general discussion in chapter 7, reflections on the findings and implications of the study will be given.
References


(26) Bailey PH. The dyspnea-anxiety-dyspnea cycle--COPD patients' stories of breathlessness: "It's scary/when you can't breathe". *Qual Health Res* 2004;14:760-78.


Chapter 2

*Health care needs in end-stage COPD:*
*A structured literature review*

Jolanda M. Habraken, Dick L. Willems, Susanne J. de Kort, Patrick J.E. Bindels

*Patient Education and Counseling* 2007; 68: 121–130
Abstract

Objective
To give an overview of relevant literature regarding health care needs in end-stage COPD and to identify specific areas where knowledge about needs is still lacking.

methods
We conducted a structured literature review. We used Bradshaw’s classification system.

Results
Seventy-seven publications were found. Ten publications were included in the review. The results reported cover 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.

Conclusion
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.

Practice implications
We especially need to focus on agreement between experts and professionals so that guidelines can be developed. To attend to the unfulfilled needs of end-stage COPD patients, the delivery of health care should be re-examined carefully.
Introduction

The demand for palliative care for patients with chronic obstructive pulmonary disease (COPD) will increase in the coming decades as a consequence of the increasing attention for palliative care and the increasing prevalence of COPD and because of an overall shift in mortality towards chronic diseases. According to the Global Burden of Disease study (GBS) of the World Health Organisation (WHO), COPD is currently the fourth leading cause of death in the world, and further increases in the prevalence and mortality of the disease can be predicted in the coming decades\(^1\). In the Netherlands, over 6300 people die from COPD yearly, 58% of whom are male and 42% female\(^2\). This accounts for almost 5% of total Dutch mortality. Palliative care historically focuses on cancer disease trajectories, and specialised services for patients with a non-malignant disease like COPD are still in a developing stage\(^3\)\(^-\)\(^5\). Palliative care focuses on maximising the quality of life of patients and their families facing problems associated with a life-threatening illness and includes care on psychological, social and spiritual dimensions.

It is important to gain more insight into the care needs of COPD patients who are going through the last part of their disease trajectory. COPD is a chronic condition that is characterised by a progressive loss of lung function with intermittent serious episodes or exacerbations\(^6\). Each exacerbation further diminishes lung capacity and this will finally result in death. However, the exact timing of death remains uncertain. The patient usually survives many such episodes. Therefore, the last phase of life for COPD patients can be very long and indistinct which makes it difficult to determine what type of supportive care is most appropriate at what time.

In this study, we show what is known in the literature about the needs of COPD patients in the end-stage of the disease. We conducted a structured literature review in order to gather all published data that address this question and identified specific areas where knowledge about needs is still lacking.

Methods

Literature search

We performed a systematic search of the literature using PubMed (1953 – March 2007) and Embase (1980 – week 12, 2007): (search date 28 March 2007). We searched all terms in PubMed as words in text, title and abstract and as MESH terms. In Embase we searched subject headings and key words. The search strategy consisted of three parts and was set up to search as sensitively as possible. The first part identified COPD patients, the second
part focussed on the terminal or palliative phase and in the last part health care needs were identified. To identify COPD patients, we used the terms chronic obstructive airway disease, chronic obstructive lung disease, chronic airflow obstruction, chronic obstructive pulmonary disease, COAD and COPD. Studies about the terminal or palliative phase were found by using the terms life support care, extraordinary treatments, life prolongation, hospice care, right to die, attitude to death, palliative treatment/care/therapy, terminally ill, terminal care, living will, severity of illness index and disease progression. Search terms for health care needs were health services needs and demand, health services research, needs assessment, needs, patient needs, wants, desire. The ‘and’ command was used to combine these three searches. The complete search strategy can be obtained from the authors.

Selection
The studies had to meet the following criteria: the study describes original data (no reviews), COPD is the main subject of study, the study is about the palliative or terminal stage of the disease, the study is about health care needs, as stated in the title or abstract of the publication and the study is written in English or Dutch. The researchers JH and DW independently evaluated the abstracts. In a few cases there was disagreement between the researchers. In those cases, consensus was reached by face-to-face discussions.

Data extraction
During the literature search, we found that the concept of health care need, although frequently used, was never clearly defined. Nevertheless, all articles included in the review reported a wide variety in themes that were all regarded as health care needs, differing from quality of life scores to ideas about place of death. In order to structure these different themes, we used Bradshaw’s classification of social need for categorizing health care needs, as has been done by other authors.
For our purpose – structuring different types of health care need as reported by different authors in different populations – none of the definitions that tried to modify Bradshaw’s classification succeeded in capturing the concept of need in a more useful way. Therefore, we decided to use his classification of need in order to structure the results reported in the selected publications. Bradshaw distinguishes four types of need that are all valid components of the concept of need. The first type of need is normative need, where experts or professionals define a desirable standard. If an individual or group falls short of
the desirable standard, then they are identified as being in need. The second type of need is felt need. When assessing need for a service, people are asked whether they feel they need it. Expressed need is felt need turned into action. Need here is defined as those people who demand a service. The last type of need is comparative need. A measure of need is found by studying the characteristics of those receiving a service. If people with similar characteristics are not in receipt of that service, then they are considered to be in need. This particular type of need is related to equity. In a later publication, Bradshaw reflected on his classification and called the type of comparative need the one least clearly described.

From the results sections of the reviewed articles, we identified all items that were related to the concept of health care need. All these items were classified as belonging to a type of need as described by Bradshaw. To prevent loss of information, we decided to use the classification of comparative need parallel to the other types of need. All items that are classified as comparative need, are also classified as one of the other three types of need.

**Results**

Seventy-seven publications were found after excluding doubles between databases. In total, 68 publications were excluded: 20 publications were not a primary investigation, 24 publications did not have COPD as the main subject, 10 did not describe the end stage of the disease, 9 did not describe health care needs, 5 were not written in English or Dutch. The nine remaining publications were included in this review. One other publication was included in the review. This publication was suggested to us by a reviewer from this journal. Unfortunately, we were unable to find this study with our search strategy. We will return to this issue in the Discussion section.

Table 2.1 describes the main characteristics of the studies that were included in the review. Almost all studies describe the results of interviews with patients or their carers. Most studies also report results from written questionnaires. All but one study were performed in the UK.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Definition of end-stage COPD</th>
<th>Method of data collection</th>
<th>Respondents</th>
<th>Research question / aim of study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cicutto⁹</td>
<td>Self-reported physician diagnosis of COPD, experience of daily symptoms that limited activities, use of inhaled bronchodilators daily; “participants saw themselves as living in the end stage of their lives”</td>
<td>Focus groups</td>
<td>Patients (N=42)</td>
<td>To gain an understanding of how people living with COPD view their world</td>
</tr>
<tr>
<td>Edmonds¹⁰</td>
<td>ICD codes 491-502</td>
<td>Interviews</td>
<td>Informal carers of deceased patients (N=87)</td>
<td>To report physical symptoms and psychosocial distress experienced by patients dying from chronic lung diseases, and services used by them during the final year of life</td>
</tr>
<tr>
<td>Elkington¹¹</td>
<td>ICD 10 codes J43.1-J44.9</td>
<td>Questionnaires</td>
<td>Proxy of deceased patients (N=209)</td>
<td>To provide a comprehensive, up to date account of the health and social service needs of a population-based sample of COPD patients in the last year of life and their contact with health services</td>
</tr>
<tr>
<td>Guthrie¹³</td>
<td>-</td>
<td>Semi-structured interviews, QoL questionnaires</td>
<td>Patients (N=35)</td>
<td>To gain an impression of experience, behaviour, feelings and judgements of patients with severe COPD</td>
</tr>
<tr>
<td>Reference</td>
<td>Definition of end-stage COPD</td>
<td>Method of data collection</td>
<td>Respondents</td>
<td>Research question / aim of study</td>
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</tr>
<tr>
<td>Jones¹⁴</td>
<td>Maximal therapy for COPD, and likely to die in the next year according to GP</td>
<td>Semi-structured interviews</td>
<td>Patients (N=16)</td>
<td>To determine prospectively the needs of patients dying in primary care from non-malignant conditions</td>
</tr>
<tr>
<td>Oliver¹⁵</td>
<td>FEV1 &lt; 50% predicted</td>
<td>Focus group, semi-structured interviews</td>
<td>Patients N=25</td>
<td>To explore the perceptions and needs of COPD patients</td>
</tr>
<tr>
<td>Robinson¹⁶</td>
<td>FEV1 &lt; 40% predicted</td>
<td>Interviews</td>
<td>Patients (N=10)</td>
<td>To describe the experience of living with severe oxygen-dependent COPD</td>
</tr>
<tr>
<td>Seamark¹⁷</td>
<td>FEV1 &lt; 40% predicted or requirement for long-term oxygen therapy</td>
<td>Semi-structured interviews</td>
<td>Patients and carers (N=10)</td>
<td>To explore the experiences of patients living with severe COPD and the impact on their carers</td>
</tr>
<tr>
<td>Skillbeck¹⁸</td>
<td>Admitted to hospital for 7 days or more with exacerbation in the last 6 months</td>
<td>In-depth interviews, QoL questionnaires, face-to-face questionnaire</td>
<td>Patients (N=63)</td>
<td>1. To identify palliative care needs in one district of those dying from COAD, and their informal carers 2. To assess the level of service use and their view of the quality of services received</td>
</tr>
</tbody>
</table>
The needs classification results are given per study, and shown in Table 2.2. The first column shows items from the result sections of the 10 included articles that are related to health care needs. The headings in bold are copied literally from the articles. In the second column, a classification in type of need according to Bradshaw is given, as interpreted by the first three authors. In case an article compared two patient populations, all items are also classified as belonging to comparative need, apart from one of the other types of need. These classifications are written in italic. In eight cases, the article includes items in the result section that are related to health care needs without sufficient information to categorize the specific item into either felt, expressed or normative need. In those cases, the corresponding type of need is classified as a question mark.

In Table 2.3, the summarized types of need according to Bradshaw are shown. All items from Table 2.2, are represented with a “+”. The items that are also classified as comparative need are represented with a “+” in ‘bold’. For eight items, there was not enough information to categorize them into one of the three types of need. These are represented in the column ‘unclear’. Table 2.3 shows that most items from the results sections report on felt need. Expressed need is studied less often, with the exception of use of care facilities. Almost none of the items concern normative need.
<table>
<thead>
<tr>
<th>References</th>
<th>Items from results sections of original articles</th>
<th>Classification of need according to Bradshaw</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cicutto⁹</td>
<td><strong>Surviving COPD</strong>&lt;br&gt;Motivation for survival from determination to stay alive, fear of dying, for the sake of family</td>
<td>Felt need</td>
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<td></td>
<td><strong>Adjusting physically</strong>&lt;br&gt;Change in lifestyle from active to sedentary</td>
<td>Expressed need</td>
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<td></td>
<td>Planning, pacing, prioritizing for activities of daily living</td>
<td>Expressed need</td>
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<td></td>
<td>Various disease management activities</td>
<td>Expressed need</td>
</tr>
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<td></td>
<td>Desire to live life and not spend all of their time on disease management activities</td>
<td>Felt need</td>
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<td></td>
<td>Need to perform exercises to help maintain function</td>
<td>Felt need</td>
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<td></td>
<td><strong>Adjusting emotionally</strong>&lt;br&gt;Having a reason for living</td>
<td>Felt need</td>
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<td></td>
<td>Need for social support (family)</td>
<td>Felt need</td>
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<td></td>
<td>Need to look on the bright side of life</td>
<td>Felt need</td>
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<td></td>
<td>Support of and need for health care providers</td>
<td>Felt need</td>
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<td></td>
<td>Peer support: the need not to feel alone with the condition</td>
<td>Felt need</td>
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<td></td>
<td>Acceptance of the disease</td>
<td>Felt need</td>
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<td></td>
<td>Having a positive attitude</td>
<td>Felt need</td>
</tr>
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<td></td>
<td>Need not to get down or depressed</td>
<td>Felt need</td>
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<td>Items from results sections of original articles</td>
<td>Classification of need according to Bradshaw</td>
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| Edmonds\(^{10}\) | **Symptoms**<br>No difference in very distressing symptoms CLD - LC<br>List of symptoms | *Felt need*<br>?
| | **Involvement of primary health care team**<br>Both groups equally satisfied with GP care<br>More help from a district nurse for LC compared to CLD<br>In both groups unmet need for nursing care at home<br>More help from a Macmillan hospice nurse compared to CLD<br>Breathlessness more often treated by GP in CLD compared to LC<br>No differences in perceptions of unmet need for treating breathlessness | *Felt need*<br>*Felt need*<br>*Felt need*<br>**Expressed need**<br>?
| | **Social care and benefits**<br>CLD needed more help with self or personal care<br>More CLD than LC received help from social services, meals on wheels and help with household tasks<br>CLD more likely to receive disability pension compared to LC<br>No difference between CLD and LC in receiving mobility allowance, attendance allowance or income support | *Expressed need*<br>*Expressed need*<br>*Expressed need*<br>*Expressed need*
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<th>Items from results sections of original articles</th>
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<tr>
<td>Edmonds[^10] (continued)</td>
<td><strong>Information and communication with health care professionals</strong>&lt;br&gt;Both groups equally satisfied with the amount of information requested or received from health care professionals&lt;br&gt;Respondents for LC more likely to have talked to hospital doctor or community nurse compared to CLD&lt;br&gt;Most respondents (both groups) knew what was wrong with deceased&lt;br&gt;Respondents of CLD more likely to have been told diagnosis by GP, compared to LC (more likely to have been told by hospital doctor)&lt;br&gt;GP gave little prognostic information (both groups)&lt;br&gt;LC more likely to get prognostic information from hospital doctor compared to CLD&lt;br&gt;LC more likely to know they were dying&lt;br&gt;LC knew they were dying for longer time compared to CLD&lt;br&gt;Both groups expressed a wish to die sooner. Of these, less than a fifth had expressed a wish for euthanasia</td>
<td><em>Expressed need</em>&lt;br&gt;<em>Expressed need</em>&lt;br&gt;?&lt;br&gt;?&lt;br&gt;<em>Expressed need</em>&lt;br&gt;<em>Expressed need</em>&lt;br&gt;<em>Felt need</em>&lt;br&gt;<em>Expressed need</em>&lt;br&gt;<em>Expressed need</em></td>
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<td><strong>Circumstances around death</strong>&lt;br&gt;CLD more likely to die in hospital compared to LC more likely to die at home / hospice&lt;br&gt;LC who died in hospital, hospices or other institutions spent longer in place of death compared to CLD, 21% of whom were in place of death &lt; 24 hours&lt;br&gt;Relatives of CLD less likely present at deceased’s death than LC relatives&lt;br&gt;Majority of relatives of CLD would have liked to have been present at deceased’s death</td>
<td>?&lt;br&gt;<em>Expressed need</em>&lt;br&gt;<em>Expressed need</em>&lt;br&gt;<em>Felt need</em></td>
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| Elkington\(^{11}\) | **Symptoms and treatment received by the deceased**  
Almost all patients had been breathless and had weakness or fatigue all the time or sometimes in the last year of life  
Other prominent symptoms include insomnia, low mood, anxiety or panic attacks, and pain  
Majority of patients with breathlessness or pain received treatment, compared to only a minority of those with psychological symptoms | Felt need                                       |
|            | **Contact with health services**  
Some informants felt that deceased subjects who had been admitted to hospital had been discharged too soon | Felt need                                       |
|            | **Informal care and social services**  
Most subjects received help from family and friends. Little help was received from health or social services, with 70% receiving none  
More informants of subjects who died at home rather than in hospital felt that they died in the right place | Expressed need                                 |
|            | **Information at the end of life**  
Almost half of informants were not aware that deceased might die. Of those, 78% would definitely or probably liked to have known  
Of the deceased, 63% definitely or probably knew he or she might die | Felt need                                       |
<p>|            |                                                                                                                                                                                                                                          | ?                                             |</p>
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<tr>
<td>Gore¹²</td>
<td><strong>Quality of life scores</strong>&lt;br&gt;COPD lower quality of life scores compared to LC patients&lt;br&gt;Similar mean number of outpatient attendances</td>
<td>Felt need</td>
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<td></td>
<td><strong>Medical care</strong>&lt;br&gt;COPD more emergency admissions per year (exacerbations) compared to NSCLC more GP contact (newly emerging symptoms)&lt;br&gt;90% of COPD and 52% of NSCLC scores suggesting depression or anxiety, but only 4% in each group received further assessment and treatment&lt;br&gt;Both groups generally satisfied with quantity of medical care and attention received. However, most patients in both groups stated they felt they were receiving all the treatment available, but that such treatment was limited in what it could offer to meet their physical and wider needs</td>
<td>Expressed need</td>
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<td><strong>Social and community care</strong>&lt;br&gt;Patients in both groups received similar financial help.&lt;br&gt;More COPD felt financial support received came late in their illness&lt;br&gt;More COPD felt they could benefit from a better provision of aids and appliances&lt;br&gt;More COPD reported lack of information regarding possible social benefits and services&lt;br&gt;None of COPD received help from specialised palliative care nurse compared to 30% of LC&lt;br&gt;COPD more likely than NSCLC to be dissatisfied with extent of help from social services and other social agents</td>
<td>Expressed need</td>
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<td>References</td>
<td>Items from results sections of original articles</td>
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| Gore\textsuperscript{12} (\textit{continued}) | Information provision  
Both groups dissatisfied because of perceived inadequate provision of information regarding illness, management, and type of social help available                                                                                   | Felt need                                      |
| Guthrie\textsuperscript{13}                   | Good QoL arises from family relationships  
Many patients’ lives were overshadowed with fear  
Patients owning a car had an advantage in keeping up leisure pursuits and shopping                                                                                           | Felt need                                      |
| Jones\textsuperscript{14}                    | **Mobility and activities of daily living**  
Breathlessness and fear of it inhibits strenuous activity, difficulty in walking up hills and climbing stairs was universally mentioned as a consequence of disease                                                               | Felt need                                      |
|                                       | **Patients’ information needs and the future course of their illnesses**  
Half of patients wanted further information about their illness, sometimes for managing their lives. Half did not.                                                                                      | Felt need                                      |
|                                       | **Impact of symptoms on patients’ lives**  
Breathlessness predominated, with the consequent lack of mobility  
Except anorexia and difficulties eating, physical symptoms were infrequent but anxieties were common, with more than half the patients expressing fear of being/becoming a burden on their carers  
Fear of dying alone                                                                                                         | Felt need                                      |
|                                       | **Attitudes to help received**  
All patients felt they knew when and how to seek help although some preferred to leave the decision to seek help to relatives  
Some patients felt that hospital admission contributed to their problems by giving them infections                                                                         | Felt need                                      |
<table>
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<th>Items from results sections of original articles</th>
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| Jones\textsuperscript{14} (continued) | **Expressed needs**  
  Lack of social contact was a problem for a few patients  
  Those patients expressing needs focused on mobility, with the lack of a stair lift or wheelchair mentioned. Many patients would not admit to needs, even when prompted to think of psychological and physical problems | Felt need |
| Oliver\textsuperscript{15} | **Beginning of the doctor-patient relationship**  
  Level of empathy and support given at the time of diagnosis | Felt need |
|  | **The agenda of the consultation**  
  Uncertainty in the progression of the disease and the unpredictable nature of the attacks of breathlessness left many patients fearing that this attack could be their last  
  Respondents received very little information from their doctors  
  Reluctance to discuss breathlessness was increased for some patients when attempting to negotiate their health care needs with their doctor  
  Majority of patients expressed the feeling of hopelessness or resignation  
  Respondents in this study identified a need for support and advice but were uncertain where to seek this help  
  The individual views of doctors varied and added to patients’ confusions | Felt need |
|  | **Illness pathway**  
  The sense of loss resulting from deterioration in lung function was a constant cause of frustration for many  
  Range and level of daily illness crises experienced by patients placed a fine line between what the patient perceived as medical and social needs  
  Patients perceived health care needs as a direct intervention based upon a severe exacerbation rather than information giving | Felt need |
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<th>Classification of need according to Bradshaw</th>
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<tbody>
<tr>
<td>Oliver[^15]</td>
<td>Social needs centred on mobility issues, coping with bouts of breathlessness in a social context, and worries about differing environments exacerbating their symptoms</td>
<td>Felt need</td>
</tr>
<tr>
<td></td>
<td>Social care needs such as washing and dressing in the morning were exhausting and required frequent breaks to recover from bouts of breathlessness</td>
<td>Expressed need</td>
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<td></td>
<td>Having purchased exercise equipment, their perceived need for supervision held them back from attempting to carry out any exercises</td>
<td>Expressed need</td>
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<td></td>
<td>Basic information to help understand diagnosis, advice and training</td>
<td>Felt need</td>
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<td></td>
<td>Many respondents went to great lengths to plan their outings in an attempt to appear ‘normal’</td>
<td>Expressed need</td>
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<tr>
<td>Medications</td>
<td>Steroids were a major source of anxiety for 11 respondents</td>
<td>Felt need</td>
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<td></td>
<td>Their concerns had not been expressed to any member of the health care team, chiefly as they did not want to be thought of as silly</td>
<td>Expressed need</td>
</tr>
<tr>
<td>Power in the doctor-patient relationship</td>
<td>Cause for concern was the need to be a ´good patient´ and not a ´nuisance´</td>
<td>Felt need</td>
</tr>
<tr>
<td>Robinson[^16]</td>
<td>Breathlessness caused some to reduce level of physical activity</td>
<td>Expressed need</td>
</tr>
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<td></td>
<td>Some patients attended pulmonary rehabilitation and while many needed encouragement to attend, they did feel a benefit</td>
<td>Expressed need</td>
</tr>
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<td></td>
<td>Some patients mentioned personal care was very difficult, causing physical and emotional problems such as frustration and fear</td>
<td>Felt need</td>
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<td></td>
<td>Support from health and social care agencies was minimal</td>
<td>Expressed need</td>
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<td></td>
<td>There appeared to be a lack of awareness of services available locally, so participants were unable to articulate their need for services that may have helped them</td>
<td>Normative need</td>
</tr>
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<td>References</td>
<td>Items from results sections of original articles</td>
<td>Classification of need according to Bradshaw</td>
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<tr>
<td>Robinson(^{16}) (continued)</td>
<td><strong>Emotional effects</strong>&lt;br&gt;Participants described frustration, fear, depression, anger and finally acceptance of a disease that they felt people did not always understand&lt;br&gt;Half of patients described feeling depressed</td>
<td>Felt need</td>
</tr>
<tr>
<td></td>
<td><strong>Needs and relationships</strong>&lt;br&gt;Participants’ main need was for information on the disease to plan ahead&lt;br&gt;Plan end-of-life issues&lt;br&gt;The physical and emotional effects of COPD had an impact on family relationships&lt;br&gt;Patients were aware that their role, status and social interactions had altered because of the disease</td>
<td>Felt need, ?, Felt need</td>
</tr>
<tr>
<td></td>
<td><strong>Symptoms</strong>&lt;br&gt;All patients described progressive dyspnoea with associated fatigue as predominant symptoms&lt;br&gt;Fear and anxiety were frequently described and anorexia and weight loss were linked to shortness of breath&lt;br&gt;Other symptoms and problems described included depression, frustration, and confusion over multiple therapies/medicines, life being ruled by medications and the dominating influence of long-term oxygen therapy&lt;br&gt;Losses&lt;br&gt;Losses related to previous activities such as job, tasks around home and garden, sport and social life&lt;br&gt;Losses with regard to the future</td>
<td>Felt need</td>
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<tr>
<td>Seamark(^{17})</td>
<td></td>
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<td>References</td>
<td>Items from results sections of original articles</td>
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| Seamark¹⁷ (continued)| **Relationships with health care professionals**  
   In some cases it appears that patients deduced their prognosis from health professional contacts, rather than having an open discussion about it, but most patients acknowledged the severity and terminal nature of their illness  
   A tension existed for patients and carers regarding role of hospital clinics, specialist respiratory nurses and the overall place of disease monitoring and surveillance  
   Patients expressed a wish for more frank and open communication and regular surveillance | Felt need (n=46)  
   ? (n=9) |
|                     | **Effect on the carer**  
   Carers expressed similar losses to patients in terms of social life, shared experiences and the future they had previously expected | Felt need |
|                     | **Adaptation**  
   Although patients’ initial responses to illness experience were mostly negative, after reflection more positive features emerged | Felt need |
| Skillbeck¹⁸         | **Current provision of health and social services**  
   On the whole, care was well evaluated, however, it must be noted that satisfaction with care did not always reflect care/service delivery that was appropriate to the needs of this group of people, as identified through the interviews | Normative need |
|                     | **Hospital-based care**  
   All patients had been admitted to hospital in the last 6 months, main reason being acute exacerbation  
   3% of patients thought hospital based care was poor, 3% thought it was fair  
   3% of patients thought outpatient care was fair | Expessed need  
   Felt need  
   Felt need |
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<th>Items from results sections of original articles</th>
<th>Classification of need according to Bradshaw</th>
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<tr>
<td>Skillbeck$^{18}$ &lt;br&gt; (continued)</td>
<td><strong>General practitioner</strong>&lt;br&gt;84% of patients had GP contact in the last three months&lt;br&gt;47% of visits were to treat a chest infection, 26% for emergency call and 2% for emotional support&lt;br&gt;13% of patients thought that GP-care was fair or poor</td>
<td>Expressed need&lt;br&gt;Expressed need&lt;br&gt;Felt need</td>
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<td></td>
<td><strong>Practical and financial support</strong>&lt;br&gt;Most patients received practical aids and financial benefits, but most had ‘struggled’ to achieve this level of support. When asked, most would have liked more information and help in making a claim</td>
<td>Expressed need</td>
</tr>
<tr>
<td></td>
<td><strong>Visits from health and social care agencies</strong>&lt;br&gt;Support from the health and social care agencies appeared to be low&lt;br&gt;Nature of the task (undertaken by district nurse) did not appear to reflect the emotional and social needs of the individuals</td>
<td>Expressed need&lt;br&gt;Normative need</td>
</tr>
<tr>
<td></td>
<td><strong>The experience of living with COAD</strong>&lt;br&gt;Most distressing and debilitating symptom is extreme breathlessness. Also reported: pain, fatigue, difficulty sleeping and thirst.&lt;br&gt;The presence of symptoms highlights that they were not receiving effective symptom control&lt;br&gt;Quality of life scores:&lt;br&gt;Reduced physical functioning and low level of social functioning&lt;br&gt;Emotional function related to a sense of loss and were often connected to being unable to undertake roles that had once been an accepted part of life</td>
<td>Felt need&lt;br&gt;Normative need&lt;br&gt;Felt need&lt;br&gt;Felt need</td>
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*CLD: Chronic lung disease, LC: Lung cancer, QoL: Quality of Life, COPD: Chronic Obstructive Pulmonary Disease, NSCLC: Non small cell lung cancer, COAD: Chronic Obstructive Airways Disease, in italics comparative need*
Table 2.3.  *Aggregated items classified by type of need*

<table>
<thead>
<tr>
<th></th>
<th>Felt need</th>
<th>Expressed need</th>
<th>Normative need</th>
<th>Unclear</th>
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<tbody>
<tr>
<td>Symptoms</td>
<td>++++++++++++++++</td>
<td>+++</td>
<td>+</td>
<td>+</td>
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<td>Quality of life</td>
<td>++++++++++++++++++</td>
<td>+++++</td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>Satisfaction with care</td>
<td>+++++</td>
<td></td>
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<tr>
<td>Information</td>
<td>+++++++++++</td>
<td>+++</td>
<td>+</td>
<td>++</td>
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<tr>
<td>Communication</td>
<td>+++</td>
<td>+++</td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>Use of care facilities</td>
<td>+++++</td>
<td>++++++++++++</td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>Type of care professional involved</td>
<td>+</td>
<td>+++++</td>
<td></td>
<td>++</td>
</tr>
<tr>
<td>Place of death</td>
<td>++</td>
<td>++</td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>Hospital admissions / attendances</td>
<td>++</td>
<td>+++++</td>
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*All items from Table 2.2. are represented with a “+”. The items that are also classified as comparative need are represented with a “+” in ‘bold’.*

**Felt need**

*Symptoms* and *quality of life* were the most frequently mentioned elements of felt need. As *symptoms*, breathlessness was mentioned often, together with emotional effects such as fear and depression.

With regard to *quality of life*, not only specific quality of life scores were reported – which are very low for end stage COPD patients – but also more general issues such as the great impact of the disease on daily life. For example, some patients mentioned a fear of dying alone and problems as a result of the lack of social contact. Other examples are the importance of accepting the disease and having a positive attitude.

The subject *information* contains items about the need for more or better information regarding illness, disease management and type of social help available. Some articles report specifically about lack of information regarding prognosis and timing of death.

Items relating to *satisfaction with care* were also frequently mentioned as elements of felt need. Usually, COPD patients tend to be very satisfied with the care they received. One
article put forward however, that patients thought that – although they were receiving all treatment available – such treatment was limited in what it could offer to meet their physical and wider needs. The use of care facilities is a subject that contains many different items. Most respondents felt that the provision of support or aids and appliances could be improved, for instance (as mentioned in one study) by getting support earlier in the disease.

**Expressed need**

With regard to expressed need, most studies report about whether or not respondents received treatment or some kind of support for their illness (i.e. social services, mobility allowance, information, specialised palliative care). Overall, end-stage COPD patients received little support from health or social services, especially when compared to other diseases (mostly lung cancer). Patients received less help with emotional problems than with physical complaints.

Examples concerning quality of life in the domain of expressed need specifically focus on the activities patients have to conduct in order to manage their disease in every day life. The change in lifestyle that is necessary for successfully managing daily life was also mentioned.

As to the type of professional involved, only items that compare end stage COPD patients to other patients are included. The items report specifically on the type of professional that was involved in the care for COPD patients compared to other patients. The emphasis here is on the professional, and not on the content of care. COPD patients receive less help from a specialised palliative care nurse compared to lung cancer patients. Lung cancer patients are more likely to receive information from a hospital doctor compared to COPD patients.

The subject hospital admissions / attendances includes items about whether or not COPD patients were admitted to or attended outpatient clinics. Overall, COPD patients have frequent hospital admissions, usually due to exacerbations.

**Normative need**

As is shown in Table 2.3, very few items were found relating to normative need. None of those items represent a desirable standard formulated by professionals or experts, as the definition of Bradshaw implies. The items represent statements by the researcher, without referring to a commonly accepted standard. For example, one author states, after
reporting on symptoms of COPD patients, that “this highlights that they were not receiving effective symptom control”. Another author states that “on the whole, care was well evaluated, however, it must be noted that satisfaction with care did not always reflect care/service delivery that was appropriate to the needs of this group of people, as identified through the interviews”.

**Comparative need**

Two articles compared COPD and lung cancer patients. The items from these studies are classified as comparative need, as well as either felt, expressed or normative need. In Table 2.3 these items are represented as bold. The items belonging to comparative need cover a wide range of subjects, with an emphasis on *use of care facilities*. The items relating to symptoms in this classification, compare symptoms between COPD and lung cancer patients. The two studies showed no differences between these two patient groups in the occurrence of very distressing symptoms, nor in perceptions of unmet need for treating breathlessness.

All items relating to *type of professional involved* obviously belong to comparative need. Also almost all the items regarding *place of death* are reported as comparative need. COPD patients are more likely to die in hospital, compared to lung cancer patients. The relatives of lung cancer patients are more likely to be present at the patient’s death, compared to the relatives of COPD patients.

**Discussion**

We found that very few studies have been published about the health care needs of end stage COPD patients. This is surprising, because of the high prevalence and the high burden of COPD worldwide. We identified specific areas where knowledge about needs is lacking.

The studies that have been published, predominantly report on felt need, i.e. needs that are mentioned by patients themselves. All but one study used interviews as a qualitative method of data collection. This is an appropriate method, since there is little information available on health care needs in end-stage COPD. Qualitative methods are preferable when knowledge on a subject is limited. The results found on expressed need predominantly report on the *use of care facilities*. It is questionable how much information can be gained about the health care needs of a population by simply counting the number of contacts with health professionals or the number of hospital admissions.
This information should be weighed against a standard that is commonly accepted. Because such a common standard is lacking, two studies included in this review solved this problem by comparing the population of COPD patients to a different population that has been studied more intensely before: lung cancer patients. Constructing the health care needs of a population by comparing two populations with similar characteristics is what Bradshaw called *comparative need*. These two articles show that COPD patients usually have lower quality of life scores compared to lung cancer patients, and have less access to specialised palliative care services. The comparisons about the number of hospital admissions or contacts with health care providers are more difficult to interpret. Following Bradshaw’s definition, when two populations are comparable and only one of the populations is in receipt of a service, the other one is in need. The difficulty always lies in establishing whether two populations are indeed comparable in this sense. COPD and lung cancer patients are comparable in the sense that they are both confronted with an airway disease that is life threatening. Both diseases are directly related to smoking. However, there are differences as well, most prominently related to a different disease trajectory\(^6\). Therefore, it seems unlikely that the health care needs of lung cancer patients are directly translatable to COPD patients.

We focused on what is known about health care needs of end-stage COPD patients as described in primary research. After classifying the items into types of need, especially a lack of knowledge on normative need became visible. When we look at the three most important guidelines (NICE\(^19\), GOLD\(^20\) and a National (Dutch) guideline\(^21\), the lack of normative need we found in this review is confirmed. The guidelines particularly mention recommendations about treatment options for very severe COPD patients, including the use of corticosteroids, long term oxygen therapy, opioids, nutrition supplement, ventilation, lung transplantation and lung volume reduction therapy. Other recommendations are about specific symptom control, the management of exacerbations and the overall management of COPD. The Dutch guideline states that there is little research published about the needs of COPD patients in the palliative and terminal phase. Also, the GOLD guideline states that further research is needed about the needs of end-stage COPD patients\(^20\). From the literature that is available, these guidelines conclude that quality of life and the number of symptoms are comparable to those of lung cancer patients\(^21\).
The lack of results on normative need also shows that the knowledge about health care needs in end-stage COPD is still developing, and has not been implemented yet. Overall, we conclude that in COPD guideline development, there should be more attention for patients needs of care in the end-stage of the disease. As we can see from this review, there are important data regarding felt need that will make a valuable ingredient for such guidelines.

Our study has a number of limitations. Since prognosis is so difficult in COPD patients and because there is no commonly accepted definition of the end-stage of the disease, a comparison between articles is difficult. The articles we included in this review all used different definitions, ranging from no definition at all to a prognosis made by the general practitioner that the patient was likely to die within one year. The difficulties in prognosis also made our literature search more complicated. It seems that authors are reluctant to provide keywords that point towards the end-stage or the palliative stage of COPD, even though it is apparent that the results are indeed applicable to patients in this phase. By adding the keywords ‘severity of illness index’ and ‘disease progression’, we tried to search as sensitively as possible to find literature concerning the end-stage. However, the article by Oliver et al.\textsuperscript{15} was not found by our search strategy. This particular article has keywords that do not in any way point towards an advanced stage of illness. This is not only a problem in this review, but also for fellow researchers who want to find literature concerning this patient group. We therefore strongly recommend authors to consider their choice of keywords carefully and not to avoid keywords that suggest the terminal or palliative phase.

Nine of the 10 articles included in this study report on only a very small number of (English) patients. All nine are qualitative studies and – although they generate useful knowledge about health care needs – cannot be statistically generalised to all COPD patients.

A generally accepted definition of the concept of health care needs is lacking, which makes comparisons between articles difficult. In the literature, numerous definitions of health care needs exist\textsuperscript{7,22,23}. By using a classification system, we did manage to compare articles about health care needs. We recommend however, that authors give a clear definition of health care needs or – rather – do not use the concept at all but specify the focus of their research.
Conclusions
We conclude that the literature about the health care needs of patients in the end-stage of COPD is sparse, and that there is no commonly accepted definition of health care needs. Few studies have been published that report about health care needs in the end-stage of COPD, and their results cover a wide range of subjects, all regarded as health care needs. This review identified a remarkable lack of knowledge about normative need (when experts or professionals define a desirable standard). Looking at the increasing demand for end of life care for COPD patients that is expected in the coming decades, there is a clear need for further research on this subject.

Practice implications
We especially need to focus on agreement between experts and professionals so that guidelines can be developed with specific attention to health care needs in the end-stage of COPD. The results from this review can be regarded as the first ingredients for such guidelines. Keeping the limitations of the study in mind, end-stage COPD patients still appear to have needs that are not being fulfilled at the moment. These needs are particularly visible in a lack of social contact, a lack of (prognostic) information, a lack of attention for emotional problems and in a lack of possibilities to die at home. To be able to attend to those needs, the delivery of health care should be re-examined carefully.
Acknowledgements
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References


Chapter 3

Health-related quality of life in end-stage COPD and lung cancer patients

Jolanda M. Habraken, Gerben ter Riet, Justin M. Gore, Michael A. Greenstone, Els J.M. Weersink, Patrick J.E. Bindels and Dick L. Willems

Abstract

Historically, palliative care has been developed for cancer patients and is not yet generally available for patients suffering from chronic life-limiting illnesses, such as chronic obstructive pulmonary disease (COPD). To examine whether COPD patients experience similar or worse disease burden in comparison with non-small cell lung cancer (NSCLC) patients, we compared the health-related quality of life (HRQOL) scores of severe COPD patients with those of advanced NSCLC patients. We also formally updated previous evidence in this area provided by a landmark study published by Gore et al. in 2000. In updating this previous evidence, we addressed the methodological limitations of this study and a number of confounding variables. Eighty-two GOLD IV COPD patients and 19 Stage IIIb or IV NSCLC patients completed generic and disease-specific HRQOL questionnaires. We used an individual patient data meta-analysis to integrate the new and existing evidence (total n = 201). Finally, to enhance between-group comparability, we 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 were found for physical functioning, social functioning, mental health, general health perceptions, dyspnea, activities of daily living, and depression. All differences favored the NSCLC patients. The sensitivity analysis, using only terminal NSCLC and COPD patients, confirmed these findings. In conclusion, end-stage COPD patients experience poor HRQOL comparable to or worse than that of advanced NSCLC patients. We discuss these findings in the light of the notion that these COPD patients may have a similar need for palliative care.
Introduction
Palliative care historically focuses on cancer disease trajectories, and specialized services for patients with a nonmalignant disease, such as chronic obstructive pulmonary disease (COPD) are still in a developing stage\textsuperscript{1,2}. However, it is increasingly recognized that palliative care may be the most appropriate approach for patients in the terminal stages of any illness\textsuperscript{3}. This holistic approach, which targets physical, psychological, social, and spiritual dimensions, strives to maximize the quality of life of patients and their families during the final stages of life\textsuperscript{4}. Studies in end-stage COPD patients have shown that many of them experience considerable problems in daily life. These problems specifically concern breathlessness, maintenance of a sufficient level of daily activities, access to information about COPD and its prognosis, perceived dependency on others, and adaptation to the illness\textsuperscript{5–12}. Consequently, COPD is increasingly being recognized as a high-priority area. In the United Kingdom, the Healthcare Commission published a national study bringing together much of the evidence on COPD care needs, culminating in the announcement of a new National Service Framework for COPD\textsuperscript{13}. The report confirms that palliative care is not yet generally considered for COPD patients, despite the need for it\textsuperscript{13}. One study about end-of-life care, on which the Healthcare Commission based some of its findings, is that of Gore et al\textsuperscript{14}. This was the first published study to indicate that end-stage COPD patients may experience significantly worse health-related QOL (HRQOL) than end-stage non-small cell lung cancer (NSCLC) patients, a group widely recognized as often in need and receipt of palliative care. An accompanying editorial\textsuperscript{15} identified two key methodological limitations. First, the NSCLC patients appeared to have had a protracted interval from diagnosis and were not receiving active treatment. This may have resulted in an “atypical” sample of NSCLC patients with less advanced disease. Further, the sample only included COPD patients with a low forced expiratory volume in one second (FEV1 < 0.75 L) and at least one admission for hypercapnic respiratory failure, thereby possibly excluding more “stable” severe COPD patients. Second, women, who tend to report lower HRQOL, were overrepresented in the COPD sample and the statistical analysis did not account for this\textsuperscript{16,17}. In our study, using an individual patient-data meta-analytic (IPD-MA) approach (including the original data from Gore et al.\textsuperscript{14}), we attempted to address these methodological limitations. Our primary objective was to compare self-reported HRQOL data of end-stage COPD patients with Global Initiative for Chronic Obstructive Lung Disease (GOLD) Stage IV and end-stage NSCLC patients (Stage IIIb or IV).
Methods

Patients
The inclusion criteria for COPD patients were a diagnosis of GOLD Stage IV (defined as an FEV1 of less than 30% of the predicted value) and age 60 years or older. We attempted to reach a more stable COPD population and, therefore, did not include Gore et al.’s criterion of at least one admission for hypercapnic respiratory failure (not usually a reason for admitting end-stage COPD patients in current practice). COPD patients were identified from medical records of outpatient clinics of four participating hospitals and one center specializing in asthma and COPD. The inclusion criteria for NSCLC patients were a diagnosis of NSCLC Stage IIIb or IV and age 60 years or older. NSCLC patients were identified by pulmonologists in the participating hospitals. Coexistence of lung cancer and COPD was an exclusion criterion. All patients provided written informed consent. The medical ethics committee of the Amsterdam Medical Centre reviewed the protocol and decided that, as the study consisted of interviews and questionnaires only, it did not require formal ethical review according to Dutch law.

Health-related quality of life measurements
All patients completed the Short Form-36 (SF-36) Health Survey\textsuperscript{18}. This generic tool has been validated in a variety of conditions and served as our main outcome measure. The SF-36 is transformed to a scale that ranges from 0 to 100, where 0 denotes the worst and 100 the best possible outcome. Because earlier research has shown a high level of anxiety and depression in COPD patients, both patient groups completed the Hospital Anxiety and Depression Scale (HADS)\textsuperscript{19}. The HADS scores are transformed to a scale that ranges from 0 to 21, where a higher score indicates more anxiety or depression. Both groups also completed validated disease-specific questionnaires. The COPD patients filled in the St George’s Respiratory Questionnaire (SGRQ)\textsuperscript{20}. This questionnaire has four domains: symptoms, impacts, activities, and a total score. Scores are transformed into percentage points; higher scores indicate a worse HRQOL. The NSCLC patients filled in the core questionnaire (Quality of Life Questionnaire [QLQ]-C30)\textsuperscript{21} of the European Organisation for Research and Treatment of Cancer (EORTC) and the lung cancer supplement (QLQLC13). The EORTC QLQ-C30 has five main functioning categories and one global score. These scores are also transformed into percentage points, a higher score indicating a better HRQOL. To obtain an indication of functional status, all patients filled in the self-report version of the Karnofsky Performance Status (KPS)\textsuperscript{22} and the The Groningen
Activities of Daily Living Restriction Scale (GARS)\textsuperscript{23}. The Karnofsky score ranges from 0 (death) to 100 (no complaints, no evidence of disease). The GARS measures activities of daily living (ADL: personal care) and instrumental activities of daily living (IADL: domestic activities). The GARS sum score has a range from 18 to 54, where higher scores indicate worse daily functioning. Because of the important role of dyspnea, we also included the Medical Research Council (MRC) dyspnea scale\textsuperscript{24}. This scale has been used for several years to grade the effect of breathlessness on daily activities. The scale ranges from 1 to 5, where higher scores indicate worse daily functioning.

**Statistical analysis**
Univariate analysis was used to compare the groups, and the Mann-Whitney U test was performed to explore the statistical significance for skewed data. The effect of the type of illness (COPD or NSCLC) on the median of the HRQOL scores was analyzed using bootstrapped quantile regression, adjusting for sex, age (continuous), and data set (Gore or Habraken). Quantile regression was used to deal with the skewness of the HRQOL data not amenable by transformation of the data\textsuperscript{25,26}. In all analyses, a level of statistical significance of 0.05 was used. All analyses were performed using SPSS for Windows (Release 14.0.1, SPSS Inc., Chicago, IL) and Stata Statistical Software, release 9 (Stata Corp LP, College Station, TX).

**Individual Patient-Data Meta-Analysis and enforcement of comparability**
First, we describe the findings of the new study. Then, using IPD-MA\textsuperscript{27-29}, we integrate the new evidence with the existing evidence produced by Gore et al. in 2000\textsuperscript{14}. We searched PubMed to find other studies comparing HRQOL of COPD and lung cancer patients, but none was found. The IPD-MA enabled us to adjust for any differences in sex and age distribution at the patient level while maintaining a strict separation of the two data sets through the use of a dummy variable. Scatterplots were used to find if age could be modeled as a continuous variable to avoid model misspecification. Finally, to further enhance comparability with regard to the state of “terminality” between the two patient groups, we performed a sensitivity analysis in those patients from the new study population who had died within one year after completing the questionnaires.
Results

Patient characteristics

Our sample consisted of 82 GOLD IV COPD patients and 19 Stage IIIb or IV NSCLC patients. Age, sex, and body mass index were similar in both groups (Table 3.1). NSCLC patients had better FEV1 values (note that only 10 NSCLC patients are included in this FEV1 analysis, as spirometry is not a routine procedure in lung cancer patients unless radical treatment is contemplated). NSCLC patients also scored more favorably on the KPS and the MRC dyspnea scale (Table 3.1). Fifteen NSCLC patients were receiving active treatment in terms of chemotherapy or radiotherapy. From the 19 NSCLC patients, 14 (74%) died within one year after completing the questionnaires. In the COPD group, 19 from the 82 COPD patients (23%) died within one year. Forty-one (50%) COPD patients and 11 (58%) NSCLC patients were admitted to hospital because of pulmonary problems in the previous year before study entry.

Table 3.1. Demographic characteristics and data related to lung function, performance status, smoking history and dyspnoea score of the patient population

<table>
<thead>
<tr>
<th></th>
<th>COPD</th>
<th>NSCLC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>82</td>
<td>19</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>69.5 (6.7)</td>
<td>69.6 (6.9)</td>
</tr>
<tr>
<td>Male n (%)</td>
<td>54 (66)</td>
<td>12 (63)</td>
</tr>
<tr>
<td>Female n (%)</td>
<td>28 (34)</td>
<td>7 (37)</td>
</tr>
<tr>
<td>Mean FEV1 (SD)</td>
<td>0.68 (0.2)</td>
<td>2.21a (0.9)</td>
</tr>
<tr>
<td>Mean KPS (SD)</td>
<td>62.0 (13.0)</td>
<td>74.2 (14.3)</td>
</tr>
<tr>
<td>Median number of pack years (IQR)</td>
<td>37.5 (22.5 – 49.38)</td>
<td>39.0 (20.0 – 50.0)</td>
</tr>
<tr>
<td>Mean BMI (SD)</td>
<td>22.9 (3.8)</td>
<td>24.2 (3.0)</td>
</tr>
<tr>
<td>Median MRC dyspnoea scale (IQR)</td>
<td>4.0 (4.0 – 5.0)</td>
<td>2.0 (1.0 – 3.0)</td>
</tr>
</tbody>
</table>

BMI = Body Mass Index; SD = Standard deviation

a Based on 10 patients

Results from the new study population

Generic health-related quality of life.

Large differences were found in the SF-36 domains of physical functioning (median: 10 vs. 50 for COPD and NSCLC patients, respectively; P < 0.0001) and general health (median: 21 vs. 30 for COPD and NSCLC patients, respectively; P = 0.032), suggesting better physical
functioning and general health for NSCLC patients. The other SF-36 dimensions were similar in both groups. Table 3.2 shows that the results on the domains role physical and role emotional were particularly skewed.

**Table 3.2. SF-36 dimension scores for patient groups**

<table>
<thead>
<tr>
<th>Patient group</th>
<th>Physical functioning (Median, IQR)</th>
<th>Role physical (Median, IQR)</th>
<th>Bodily pain (Median, IQR)</th>
<th>General health perceptions (Median, IQR)</th>
<th>Vitality (Median, IQR)</th>
<th>Social functioning (Median, IQR)</th>
<th>Role emotional (Median, IQR)</th>
<th>Mental health (Median, IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD n=82</td>
<td>10 (0-25)</td>
<td>0 (0-0)</td>
<td>62 (41-100)</td>
<td>21 (14-35)</td>
<td>40 (29-60)</td>
<td>38 (25-75)</td>
<td>50 (0-100)</td>
<td>68 (48-80)</td>
</tr>
<tr>
<td>NSCLC n=19</td>
<td>50 (25-75)</td>
<td>0 (0-25)</td>
<td>74 (41-80)</td>
<td>30 (20-42)</td>
<td>40 (20-65)</td>
<td>63 (25-75)</td>
<td>33 (0-100)</td>
<td>72 (40-80)</td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;0.0001</td>
<td>0.452</td>
<td>0.559</td>
<td>0.032</td>
<td>0.927</td>
<td>0.374</td>
<td>0.309</td>
<td>0.651</td>
</tr>
</tbody>
</table>

*a Scale: 0-100%

*b Higher scores indicate better outcome

Anxiety and depression were similar in both patient groups (Table 3.3). Clinically significant anxiety (a score of 8 or higher) was present in 42% of the COPD patients and also in 42% of the NSCLC patients. Clinically significant depression was present in 49% of the COPD patients and in 32% of the NSCLC patients. Table 3.4 shows that COPD patients experienced significantly more problems than their NSCLC counterparts in ADL (median: 18 vs. 12 for COPD and NSCLC patients, respectively; P < 0.001) and instrumental ADL (median: 16 vs. 12 for COPD and NSCLC patients, respectively; P = 0.006).
Table 3.3.  *Anxiety and depression scores for patient groups*  

<table>
<thead>
<tr>
<th></th>
<th>Anxiety</th>
<th></th>
<th>Depression</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>(IQR)</td>
<td>Median</td>
<td>(IQR)</td>
</tr>
<tr>
<td>COPD: n=82</td>
<td>6</td>
<td>(3-10)</td>
<td>7</td>
<td>(4-11)</td>
</tr>
<tr>
<td>NSCLC: n=19</td>
<td>7</td>
<td>(4-10)</td>
<td>6</td>
<td>(4-9)</td>
</tr>
<tr>
<td>P-value</td>
<td>0.641</td>
<td></td>
<td>0.228</td>
<td></td>
</tr>
</tbody>
</table>

*aHigher scores indicate more anxiety or depression*

Table 3.4.  *GARS scores for patient groups*  

<table>
<thead>
<tr>
<th></th>
<th>ADL</th>
<th>IADL</th>
<th>Sumscore</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>(IQR)</td>
<td>Median</td>
</tr>
<tr>
<td>COPD: n=82</td>
<td>18</td>
<td>(15-22)</td>
<td>16</td>
</tr>
<tr>
<td>NSCLC: n=19</td>
<td>12</td>
<td>(11-17)</td>
<td>12</td>
</tr>
<tr>
<td>P-value</td>
<td>&lt; 0.001</td>
<td>0.006</td>
<td>0.002</td>
</tr>
</tbody>
</table>

*aHigher scores indicate fewer activities of daily living*

**Disease-specific health-related quality of life.**

The median (interquartile range [IQR]) SGRQ domain scores for the COPD group were as follows–symptoms: 59 (45-76); activity: 86 (79-93); impact: 60 (40-71); and total: 68 (54-76). The median (IQR) EORTC QLQ-C30 domain scores for the NSCLC patients were as follows–global health: 50 (42-83); physical functioning: 60 (40-87); role functioning: 50 (17-67); emotional functioning: 75 (33-83); cognitive functioning: 83 (67-83); and social functioning: 67 (17-100).

**Results from the Individual Patient-Data Meta-Analysis (IPD-MA)**

To update the available evidence in the light of our latest findings, we combined the new data set with that of Gore et al.  

Table 3.5 describes characteristics of COPD and NSCLC patients from both data sets. The characteristics of the lung cancer patients are similar in both databases, except that the COPD patients from Gore et al.’s database have lower
FEV1 values and a higher proportion of women compared with the new database. The SF-36 and the HADS were filled in by COPD and NSCLC patients and were available in both data sets. Therefore, these questionnaires were used in the multivariable regression analysis. Because of the extremely skewed distribution in the SF-36 domains role physical and role emotional, we left these two domains out of the quantile regression analysis.

Table 3.5. *Demographic characteristics and lung function of COPD and NSCLC patients used for IPD-MA*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>COPD</th>
<th>NSCLC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>Habraken et al.</td>
<td>Gore et al.</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>82</td>
<td>(6.7)</td>
</tr>
<tr>
<td>Male n (%)</td>
<td>54</td>
<td>(66)</td>
</tr>
<tr>
<td>Female n (%)</td>
<td>28</td>
<td>(34)</td>
</tr>
<tr>
<td>FEV1 (SD)</td>
<td>0.68</td>
<td>(0.2)</td>
</tr>
</tbody>
</table>

*SD = standard deviation
*aBased on 10 patients

Figure 3.1 is based on the multivariable regression analysis. Controlled for data set, age, and sex, differences in HRQOL between the COPD and NSCLC patients tended to be in favor of the NSCLC patients (Fig. 3.1). All estimates on the left side of the vertical line and, in particular, their upper 95% confidence limits indicate a difference in favor of the NSCLC patients. The domain physical functioning shows a difference of 20% in favor of the NSCLC patients. Fig. 3.1 shows that the COPD patients never score favorably on QOL compared with the NSCLC patients on virtually all dimensions. In particular, there is evidence that COPD patients’ QOL is worse on five of eight scales. For anxiety, the results from the new database were significantly different from those of Gore et al.’s database (P value for interaction = 0.002). Therefore, in Fig. 3.1, the anxiety results from both databases are shown separately. In Gore et al.’s database, NSCLC patients had less anxiety, whereas in the new database, anxiety levels tended to be similar (as described earlier in the section “Results from the New Study Population”). The interaction between anxiety and type of database was statistically significant. We studied the interactions for all other variables, but none were found. Overall, Fig. 3.1 shows that, for COPD patients, the QOL never appears better than that of the NSCLC patients.
Figure 3.1. **IPD-MA results for SF-36 and HADS scores for COPD and NSCLC patients (N = 201)**

![Graph showing differences in SF-36 and HADS scores between COPD and NSCLC patients.](image)

*Interaction between anxiety and type of database was significant (P = 0.002). HADS scores are transformed from positive to negative for visual purposes. The analyses were controlled for age (continuous), sex and type of database (both as dummy variables). The vertical line at 0 indicates no difference.*

**Restriction to those patients in the new data set who had died within one year**

To further enhance the comparability of disease severity between the two patient groups, we performed a sensitivity analysis on those patients from the new study population who had died within one year after completing the questionnaires. This subsample consists of 19 COPD patients and 14 NSCLC patients. Figure 3.2 shows the results from this analysis. The domain physical functioning shows a difference of 36% in favor of the NSCLC patients, and for general health perceptions, the difference is 17%. Overall, the trend toward a more favorable outcome for the NSCLC patients remains, although it is somewhat less marked for the domains vitality and social functioning. The domain mental health appears to shift more toward favoring COPD patients, although the confidence interval is wide.
Figure 3.2. SF-36 and HADS scores for COPD and NSCLC patients who died within one year after completing the questionnaires (N = 33; Habraken et al. data set only)

HADS scores are transformed from positive to negative for visual purposes. The analyses were controlled for age (continuous) and sex (dummy variables). The vertical line at 0 indicates no difference.

Discussion

The main aim of our study was to compare self-reported HRQOL data of end-stage COPD patients (GOLD IV) and end-stage NSCLC patients (Stage IIIb or IV) after addressing a key question arising out of Gore et al.’s previous research. Once we control for possible confounding variables, do the results hold up? Our study suggests that when we compare relatively more stable end-stage COPD patients with advanced NSCLC patients, and ensure sex distributions are appropriate, COPD patients still appear to experience a poor HRQOL, similar to, and in some cases, significantly worse than, that of terminal lung cancer patients. The COPD group particularly appeared to perceive its general health as worse and to suffer more greatly in terms of physical functioning, social functioning, and ADL. These are the domains that emerge from previous studies. Because of the protracted nature of the end-stage of COPD, the problems they experience in these domains are particularly worrying. Recent recommendations have called for palliative care approaches to consider including chronic diseases, such as COPD. Moreover, although there has been
some progress, there is still a dearth of information on how best to meet the varying needs of such patients\textsuperscript{30}. If there is evidence that COPD patients have similar HRQOL as lung cancer patients who are among the traditional recipients of palliative care, this may be used to stimulate the development of palliative approaches in COPD. Further, as dyspnea is a central factor in the COPD experience, evidenced by the MRC, SF-36 physical functioning, and ADL values, as well as a previous research\textsuperscript{14,31,32}, such COPD palliative approaches should include symptom management and the instruction of tailored coping strategies to reduce breathlessness. The sex ratio in our sample, favoring males, was comparable between COPD and NSCLC patients and representative of general prevalence rates\textsuperscript{15}, including those in The Netherlands\textsuperscript{33}. Although women are increasingly being diagnosed with COPD, and historically, there may have been gender bias in the diagnostic process\textsuperscript{16}, COPD prevalence rates are generally higher in males\textsuperscript{17}. The COPD patients in our study were selected only on FEV1 values, in line with the GOLD criteria, without the criterion of hospital admission for hypercapnic respiratory failure. Therefore, compared with Gore et al\textsuperscript{34}, we have selected a more diverse COPD group, including more stable patients (in line with Hill and Meurs’ recommendation\textsuperscript{15}). NSCLC patients were selected on the basis of having Stage IIIb or IV disease, and 79% were undergoing active treatment, whereas 74% died within one year after completing the questionnaires. This indicates that our sample was more representative of “typical” NSCLC patients. To further enhance the comparability between the groups in terms of “terminality,” we conducted a sensitivity analysis in those patients who died within one year after completing the questionnaires. A similar pattern to the main results was found, supporting the notion that HRQOL of end-stage COPD patients is not superior to that of end-stage NSCLC patients. However, because of the small number of patients in this sensitivity analysis, the confidence intervals are wider and cannot fully exclude small differences in favor of COPD. The HADS suggested little difference between the groups in terms of anxiety and depression. This contrasts with Gore et al.’s study, which found the COPD group members to be suffering from significantly worse anxiety and depression than their NSCLC counterparts. Possibly, the higher proportion of females in Gore et al.’s COPD sample acted as a confounder\textsuperscript{34,35}. However, once we combine the two data sets and control for sex and age, again, depression appears more prevalent in the COPD group. In addition, our meta-analysis indicates that HRQOL in the other domains is indeed significantly worse in COPD, or at best, similar to the NSCLC group, once such confounders have been accounted for. Our study has some limitations. First, we encountered difficulties in obtaining fully up to-date
FEV1 values by means of the medical records. We found that, in this group of severe COPD patients, spirometry was not performed on a regular basis. In 55% of the COPD patients, the most recent FEV1 value was determined during the past one year. For the other COPD patients, the most recent spirometry values dated back one to nine years. However, because COPD is a progressive disease, we can assume that, for most patients, FEV1 values were even worse at the time of study entry than the most recently documented ones. Furthermore, for the COPD patients, FEV1 values were rarely explicit in being pre- or post-bronchodilator values. However, as COPD is characterized by irreversible FEV1 measured by bronchodilators, it is not really important at this stage of disease if it is pre- or post-bronchodilator. Furthermore, if some patients would have been wrongfully included in our study because of pre- instead of post-bronchodilator scores, this would mean that the differences we found between COPD and NSCLC patients would be even more striking when the sample would consist of “real” GOLD IV patients, based only on post-bronchodilator values. In the NSCLC patients, spirometry was hardly ever performed in clinical practice; hence, we cannot totally exclude the possibility that some of these patients also had a degree of COPD, although the lung specialists identified NSCLC patients who they believed did not have COPD in addition. The second limitation relates to the small number of NSCLC patients. We had trouble recruiting NSCLC patients because almost all those in Stages IIIb and IV were participating in clinical trials, and specialists were reluctant to approach these patients. We cannot completely exclude the possibility that this has led to the inclusion of NSCLC patients with a slightly more favorable health status. It is, however, also possible that the lung cancer patients who were too ill to participate in clinical trials were the ones who were eligible for our study. In that case, our sample of lung cancer patients may have a less favorable health status. We do not have information about the nonresponders to test these hypotheses. The third limitation is that we have no data about what kind of therapy the COPD patients received. Although we have no reason to assume that any patients were receiving suboptimal treatment as all patients were receiving treatment from a pulmonologist we cannot completely exclude this possibility. In conclusion, this study helps to confirm that end-stage COPD patients have poor HRQOL, comparable with that of advanced NSCLC patients. Palliative care is very much focused on QOL. Therefore, if patient groups experience similar QOL, this might be an indication that they perceive a similar need for palliative care. However, a similar need for palliative care does not necessarily imply similar provision of care. There is ongoing debate about how best to apply the palliative approach to COPD. Indeed, end-
stage COPD is associated with specific challenges, such as difficulties in prognosis. Because of these specific challenges and because of the implicit transition to the palliative phase, it seems more appropriate to incorporate the palliative approach in generic health care provision than to simply widen access to specific palliative care services to facilitate COPD patients. The data from our study could be used to inform future palliative approaches in COPD, and suggest the need to particularly focus on management strategies for dyspnea and ADL. Future research, however, should further assess how best to apply the palliative approach to COPD.
Acknowledgments

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References


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Chapter 4

Health-related quality of life and functional status in patients with end-stage COPD: a prospective longitudinal study

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Submitted for publication
Abstract

Background
Although it is well known that chronic obstructive pulmonary disease (COPD) is a potentially fatal disease, there is still a dearth of information about the end-stage. Our main aim was to examine the development of HRQOL and functional status over time in COPD patients with GOLD stage IV, by using repeated measurements during one year.

Methods
82 Dutch COPD patients in GOLD stage IV completed the St George’s Respiratory Questionnaire (SGRQ) for health-related quality of life (HRQOL) and the Groningen Activities for Daily Living Restriction Scale (GARS) for functional status every three months in the year after enrolment. Survival was followed up until 5 years after enrolment. 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. Outcome measures were the development of SGRQ and GARS over time for all patients, and in those who had died within two years, and survival time. Overall and single-patient line graphs and mixed regression models were used to study the development of SGRQ and GARS. Survival was studied using Kaplan-Meier curves and univariate Cox proportional hazards models.

Results
In the majority of patients, scores on the SGRQ and GARS declined over time gradually. With few exceptions, in the subgroup of 32 patients that died within 2 years these scores also declined gradually, without steep deteriorations.

Conclusions
In patients in end-stage COPD, HRQOL and functional status deteriorate gradually over time, indicating 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.
**Introduction**

Chronic obstructive pulmonary disease (COPD) is one of the most important causes of morbidity and mortality worldwide. COPD is a progressive illness, characterised by acute episodes of illness (exacerbations). Although it is well known that COPD is a potentially fatal disease, there is still a dearth of information about the end-stage. Patients in the end-stage of COPD usually experience and survive several severe exacerbations, but any one may prove to be the fatal one. Therefore, the end-stage in COPD is hard to define. Because of this unpredictable trajectory in the end-stage of COPD, patient-physician communication about palliative and end-of-life care is unlikely to occur and, as a consequence, the death of a COPD patient may feel sudden and unexpected for both patients and family members.

Studies about the final years of patients with advanced COPD have shown that these are characterised by uncontrolled symptoms such as intolerable dyspnoea, high levels of anxiety, depression and social isolation. It is also known that, despite these uncontrolled symptoms, patients in the end-stage of COPD have limited access to specific palliative care services when compared to, for example, patients suffering from advanced lung cancer. Cross-sectional studies have shown that health-related quality of life (HRQOL) is low in these patients, even compared to advanced lung cancer patients. It is thus recognised that patients in the end-stage of COPD have care needs that are not currently being met.

Longitudinal studies assessing the course of HRQOL in the end-stage of COPD are – to our knowledge – not available. It would therefore be important to get a better understanding about the clinical course of the end-stage of COPD as expressed by the patients’ HRQOL. If COPD patients in the end-stage report significant changes in their perceived HRQOL, this may provide clinicians with tools for improving palliative care provision at the end-of-life. This would be aimed specifically at treating unmet care needs and at the timing of communication about palliative and end-of-life decisions, benefitting both patients and their informal caregivers.

Our main aim was therefore to examine the development of HRQOL and functional status over time in patients in the end-stage of COPD. We set out to explore changes in HRQOL and functional status over time, by using repeated measurements during one year in COPD patients with GOLD stage IV.
Methods

Patients
Between March 2004 and November 2006 we included 82 Dutch COPD patients in GOLD stage IV. The inclusion criteria were a forced expiratory volume in one second (FEV₁) of less than 30% of predicted, and aged 60 years or older. Patients were identified from medical records of outpatient clinics of four participating hospitals and one centre specialising in asthma and COPD, all situated in the Netherlands. Because data at baseline were compared to advanced lung cancer patients (described in detail elsewhere²¹), co-existence of stage IIIb or IV lung cancer was an exclusion criterion. Patients were asked to complete a self-administered questionnaire at baseline and every 3 months over a period of one year. After 5 years, GPs were contacted for survival information. All patients provided written informed consent. The research ethics committee of the Amsterdam Medical Centre (AMC) reviewed the complete study protocol and decided that, as the study consisted of interviews and questionnaires only, it did not require formal ethics review.

Health-related quality of life measurements
All patients completed the disease specific St George’s Respiratory Questionnaire (SGRQ)²⁴. This questionnaire has four domains: symptoms, impacts, activities and a total score. Scores are transformed into percentage points ranging from 0 to 100; higher scores indicate a worse HRQOL. For a subjective measurement of functional status, patients also completed the Groningen Activities of Daily Living Restriction Scale (GARS)²⁵. The GARS measures activities of daily living (ADL) (personal care) (range 11 – 33) as well as instrumental activities of daily living (IADL) (domestic activities) (range 7 – 28). The total score has a range from 18 to 54. Higher scores indicate worse daily functioning in all domains. Because of the important role of dyspnoea, the Medical Research Council (MRC) dyspnoea scale was also included²⁶. The scale ranges from 1 to 5, where higher scores indicate worse daily functioning due to breathlessness.

Statistical analysis
Definition of severity subgroups
Our main aim was to examine the development of HRQOL over one year in or near the end-stage of the disease. At baseline, there were considerable differences between patients both on the GARS and the SGRQ. To deal with this high inter-individual variability,
we stratified the study population in severity subgroups according to the lowest, intermediate and highest tertile of SGRQ and GARS at baseline, respectively. By stratifying on these subgroups, we corrected for possible bias due to selective dropout (see below).

**Statistical modelling**
We investigated the development of SGRQ and GARS over time using mixed models. We regressed both the total scores and subscales of SGRQ and GARS on time since baseline and severity subgroup using random intercepts and slopes. These models allowed individual patients to start at different scores at baseline and allowed their courses over time to vary individually. In addition, we included interactions between time and severity subgroup to assess if the courses differed between the three subgroups. Using these models, we investigated whether a possible decline in SGRQ and GARS over time differed according to baseline SGRQ and GARS, respectively.

**Selective dropout**
Dropout during the study was summarized numerically in a table and survival was explored by using Kaplan-Meier curves. We examined the possibility of bias in our description of the development of SGRQ and GARS due to selective dropout (due to rapid deterioration or death); individuals with poorer SGRQ or GARS might drop out sooner than individuals with better SGRQ or GARS. Therefore, during the course of the study, individuals remaining in the study could be relatively healthy. The development of SGRQ and GARS in this subselection of relatively healthy individuals would not equal the development of SGRQ and GARS in the study population.

Using univariate Cox proportional hazards models it was confirmed that both SGRQ and GARS (including all subdomains) were associated with dropout due to deterioration or death. However, the effects of SGRQ and GARS on dropout disappeared by including severity subgroup in the models (either low/intermediate/high SGRQ at baseline or low/intermediate/high GARS at baseline, respectively). This implies that by stratifying on severity subgroup, we adjusted for selective dropout. This stratification was done in two ways: Firstly by plotting the development of GARS and SGRQ over time separately for each subgroup. Secondly, by including subgroup as a covariate in the mixed models described above.
**Imputation**

Of the total number of 262 measurements that were taken in the 82 patients, there were no missing values in the SGRQ domains. However, for the Total GARS, GARS ADL and GARS IADL domains, there were 17, 12 and 13 missing values, respectively. These missing values were imputed using mixed models, regressing the GARS scales on time since inclusion and all baseline covariates, and allowing for random intercepts and slopes.

**Results**

The median time between measurements was 111 days (10\textsuperscript{th} and 90\textsuperscript{th} percentile were 97 and 140 days, respectively), which is somewhat more than the planned 3 months (91 days). Table 4.1 summarises baseline characteristics of the study population separately for each severity subgroup. There were no important differences between the subgroups with respect to demographics and lung function. However, the treatment characteristics were consistently higher in the high severity group than in the low severity group.

Table 4.2 shows the number of patients in the study population and the number of dropouts for each of the four follow-up measurements. Of the 29 patients in total who dropped out of the study, 23 died during or within 5 years after the study period. Two patients dropped out because of emotional problems with the questionnaires. Four patients were lost to follow-up. Higher severity seems to be associated with a higher dropout rate. This means that patients who entered the study with worse quality of life and worse functional status dropped out more than patients who entered the study with more favourable quality of life and functional status scores.

A higher probability of survival in the low severity subgroups is seen in Kaplan Meier curves for the six subgroups (Figure 4.1). Figure 4.1 shows the cumulative survival during 5 years from the start of the study, for all severity subgroups. At two years after entering the study, patients in the high severity subgroup have a probability of survival of 0.46 (95% CI 0.31-0.69) (based on SGRQ) and 0.53 (95% CI 0.38-0.75) (based on GARS), compared to a probability of survival of 0.70 (95% CI 0.55-0.90) (based on both SGRQ and GARS) of the low severity subgroup at the same time point.
<table>
<thead>
<tr>
<th>SGRQ at baseline (HRQOL)</th>
<th>GARS at baseline (ADL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>Intermediate</td>
</tr>
<tr>
<td>SGRQ score at baseline</td>
<td>47.3 (8.8)</td>
</tr>
<tr>
<td>GARS score at baseline</td>
<td>28.6 (6.8)</td>
</tr>
</tbody>
</table>

**Demographics**

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Intermediate</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of patients</td>
<td>27</td>
<td>27</td>
<td>28</td>
</tr>
<tr>
<td>Age mean (SD)</td>
<td>69.3 (7.2)</td>
<td>69.8 (6.4)</td>
<td>69.3 (6.9)</td>
</tr>
<tr>
<td>BMI mean (SD)</td>
<td>23.4 (3.9)</td>
<td>23.3 (2.6)</td>
<td>22.0 (4.6)</td>
</tr>
<tr>
<td>Sex Female N (%)</td>
<td>10 (37)</td>
<td>7 (26)</td>
<td>11 (39)</td>
</tr>
<tr>
<td>Living alone N (%)</td>
<td>9 (33)</td>
<td>4 (15)</td>
<td>8 (29)</td>
</tr>
</tbody>
</table>

**Lung function Median (IQR)**

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Intermediate</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEV1 % pred</td>
<td>25 (24-28)</td>
<td>25 (22-27)</td>
<td>25 (22-27)</td>
</tr>
<tr>
<td></td>
<td>26 (24-28)</td>
<td>26 (24-28)</td>
<td>25 (20-26)</td>
</tr>
</tbody>
</table>

**Treatment N (%)**

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Intermediate</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admitted to hospital in the previous year</td>
<td>12 (44)</td>
<td>13 (48)</td>
<td>16 (57)</td>
</tr>
<tr>
<td>Attended pulmonary rehabilitation therapy ever</td>
<td>10 (37)</td>
<td>15 (56)</td>
<td>13 (46)</td>
</tr>
<tr>
<td>Current use of long-term oxygen therapy</td>
<td>10 (37)</td>
<td>14 (52)</td>
<td>13 (46)</td>
</tr>
<tr>
<td></td>
<td>6 (22)</td>
<td>13 (52)</td>
<td>18 (60)</td>
</tr>
</tbody>
</table>

**Dyspnoea median (IQR)**

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Intermediate</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRC Dyspnoea scale</td>
<td>3 (1-4)</td>
<td>4 (4-5)</td>
<td>5 (5-5)</td>
</tr>
<tr>
<td></td>
<td>4 (2-4)</td>
<td>4 (4-5)</td>
<td>5 (5-5)</td>
</tr>
</tbody>
</table>

*SD = Standard deviation; BMI = Body Mass Index; FEV1 % pred = Forced expiratory volume in one second expressed in percentage of predicted; HRQOL = Health related quality of life; Higher scores on SGRQ and GARS indicate increasing severity*
Table 4.2. Total number of patients and dropouts for each of the four follow-up measurements in the year after enrolment in the three subgroups based on total SGRQ or GARS score at baseline

<table>
<thead>
<tr>
<th>Number of patients in each subgroup N (%)</th>
<th>Measurement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of patients</td>
<td></td>
<td>82 (100)</td>
<td>68 (83)</td>
<td>59 (72)</td>
<td>53 (65)</td>
</tr>
<tr>
<td>Subgroups</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Based on total SGRQ score at baseline</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td></td>
<td>27 (100)</td>
<td>25 (93)</td>
<td>23 (85)</td>
<td>23 (85)</td>
</tr>
<tr>
<td>Intermediate</td>
<td></td>
<td>27 (100)</td>
<td>22 (82)</td>
<td>19 (70)</td>
<td>18 (67)</td>
</tr>
<tr>
<td>High</td>
<td></td>
<td>28 (100)</td>
<td>21 (75)</td>
<td>17 (61)</td>
<td>12 (43)</td>
</tr>
<tr>
<td>Based on total GARS score at baseline</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td></td>
<td>27 (100)</td>
<td>23 (85)</td>
<td>22 (82)</td>
<td>22 (82)</td>
</tr>
<tr>
<td>Intermediate</td>
<td></td>
<td>25 (100)</td>
<td>21 (84)</td>
<td>19 (76)</td>
<td>16 (64)</td>
</tr>
<tr>
<td>High</td>
<td></td>
<td>30 (100)</td>
<td>24 (80)</td>
<td>18 (60)</td>
<td>15 (50)</td>
</tr>
</tbody>
</table>

Figure 4.1. Kaplan-Meier curve for low, intermediate and high severity subgroups, based on total SGRQ score and total GARS score at baseline

Boxplots of the three subgroups of both SGRQ and GARS are shown in Figure 4.2 and 4.3, respectively. In Figure 4.2, development over time of the SGRQ is shown, for each of the severity subgroups. On the activity domain, there appears to be a ceiling effect, that is, patients score so high that there is no more room for them to score even higher (worse)
on this domain. On the other domains no clear ceiling effect is apparent, although the upper limits of the confidence intervals of the high severity subgroups are close to the maximal score of 100%. What is most apparent in Figure 4.2 is that, with severity subgroups, the courses of the SGRQ domains show little difference over time. In the impacts and total domains, there is a slight shift towards a higher score on the fourth measurement, but this shift is delicate and only visible in the subgroup that entered the study with the most favourable HRQOL.

Figure 4.2. **Boxplots of the four domains of the SGRQ, by severity subgroups (based on total SGRQ score at baseline) and by measurement time point**

![Boxplots of the four domains of the SGRQ](image)

Figure 4.3 shows the development of the GARS scores. The same shallow and gradual pattern as that in Figure 4.2 can be seen. In Figure 4.3 too, the upper limits of the confidence intervals of the high severity subgroup indicate some ceiling phenomena in the IADL and Total domains in particular.
In Figure 4.4 the total SGRQ and GARS scores are presented over time for those patients who died within 2 years from the onset of the study (N=32). With very few exceptions, Figure 4.4 shows that there are no sudden changes in mean scores at the end of life.
Figure 4.4.  *Total SGRQ and total GARS scores for patients who died within 2 years after the onset of the study (N=32)*

Figure 4.5 shows exemplary plots of the development of total SGRQ and GARS scores for six individual patients. These individual plots are an illustration of the variability within our population. Patients A, B and C show score patterns that are typical for the overall trends in Figures 2 and 3. On the other hand, patients D, E and F illustrate that in some cases considerable variation in HRQOL and functional status over time may occur. The differences in scores within these patients are substantial given the fact that a difference of four in SGRQ scores is considered to be clinically significant. ²⁷
Table 4.3 shows the fixed intercepts and fixed one year increase in SGRQ and GARS scores from the mixed models described above, for all domains, and for all subgroups separately. Predicted one-year increase in SGRQ and GARS score is significant in the low and intermediate severity subgroups, except for the SGRQ symptoms domain. Predicted increases are largest in the low severity subgroups. On SGRQ, the low severity subgroup shows a statistically and clinically significant increase of 5.6 on Activity domain (CI 2.5 to 8.8), 7.0 on Impacts domain (CI 3.0 to 11.1) and 6.0 on Total domain (CI 3.2 to 8.8). On GARS, the low severity subgroup shows a statistically significant increase of 1.0 on ADL domain (CI 0.2 to 1.9), 0.9 on IADL domain (CI 0.2 to 1.6) and 2.3 on Total domain (CI 1.1 to 3.5). This means that especially those patients with a more favourable HRQOL at baseline are predicted to show the largest decrease in HRQOL after one year. On the SGRQ impacts domain also the intermediate severity subgroup is predicted to increase over four points in one year. On the GARS ADL domain, all subgroups are predicted to deteriorate statistically significant in one year.
Table 4.3. Overview of intercepts and predicted 1 year increase using longitudinal models in all domains of SGRQ and GARS for all severity subgroups separately

<table>
<thead>
<tr>
<th>Subgroups based on total SGRQ scores at baseline</th>
<th>Intercept (95% CI)</th>
<th>Predicted 1yr increase (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SGRQ: Symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>45.4 (39.3 to 51.5)</td>
<td>3.7 (-2.9 to 10.3)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>59.9 (56.0 to 63.7)</td>
<td>3.1 (-1.6 to 7.8)</td>
</tr>
<tr>
<td>High</td>
<td>74.3 (68.3 to 80.4)</td>
<td>2.4 (-5.8 to 10.6)</td>
</tr>
<tr>
<td>SGRQ: Activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>73.3 (70.2 to 76.5)</td>
<td>5.6 (2.5 to 8.8)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>84.1 (82.1 to 86.1)</td>
<td>2.9 (0.5 to 5.2)</td>
</tr>
<tr>
<td>High</td>
<td>95.0 (91.8 to 98.1)</td>
<td>0.1 (-4.0 to 4.2)</td>
</tr>
<tr>
<td>SGRQ: Impacts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>36.6 (33.3 to 39.9)</td>
<td>7.0 (3.0 to 11.1)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>56.2 (54.1 to 58.3)</td>
<td>4.5 (1.5 to 7.5)</td>
</tr>
<tr>
<td>High</td>
<td>75.9 (72.5 to 79.2)</td>
<td>1.9 (-3.4 to 7.3)</td>
</tr>
<tr>
<td>SGRQ: Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>49.6 (46.8 to 52.3)</td>
<td>6.0 (3.2 to 8.8)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>65.5 (63.8 to 67.2)</td>
<td>3.8 (1.7 to 5.9)</td>
</tr>
<tr>
<td>High</td>
<td>81.4 (78.7 to 84.2)</td>
<td>1.6 (-2.2 to 5.3)</td>
</tr>
</tbody>
</table>

Subgroups based on total GARS scores at baseline

| GARS: ADL                                      |                   |                                 |
| Low                                           | 13.9 (13.1 to 14.7) | 1.0 (0.2 to 1.9)             |
| Intermediate                                  | 18.3 (17.8 to 18.8) | 1.0 (0.4 to 1.6)             |
| High                                          | 22.7 (22.0 to 23.4) | 1.1 (0.1 to 2.0)             |
| GARS: IADL                                     |                   |                                 |
| Low                                           | 12.2 (11.6 to 12.8) | 0.9 (0.2 to 1.6)             |
| Intermediate                                  | 15.9 (15.5 to 16.3) | 0.4 (-0.1 to 0.8)           |
| High                                          | 19.6 (19.0 to 20.1) | -0.2 (-1.0 to 0.6)           |
| GARS: Total                                    |                   |                                 |
| Low                                           | 26.1 (25.0 to 27.2) | 2.3 (1.1 to 3.5)             |
| Intermediate                                  | 34.2 (33.5 to 34.9) | 1.7 (0.8 to 2.5)             |
| High                                          | 42.2 (41.1 to 43.3) | 1.1 (-0.3 to 2.5)            |
Discussion
We found that COPD patients with GOLD stage IV experience low quality of life and functional status that deteriorate slightly during at least one year. Mostly, patients who enter the study with a more favourable HRQOL and functional status show the largest and clinically significant decline over time. It is however expected that also the patients who already had a less favourable health status when entering the study experience a deterioration, even though this could not be measured accurately.
It may be expected that patients’ quality of life deteriorates rapidly prior to death because of increasing symptom burden. Our data however showed a gradual decline of HRQOL and functional status over time with no indication of a steep decline at the end of life, not even in those patients who died during the study period. This indicates that by assessing HRQOL and functional status (using SGRQ and GARS) on a regular basis, no additional information about the timing of the terminal stage is gained. Despite this, our data do suggest individual variation in HRQOL and functional status. These individual variations are probably due to exacerbations. A study by Seemungal et al. showed that in a cohort of COPD patients with slightly better lung function (mean FEV1 40% of predicted) frequent exacerbations, high levels of dyspnoea and daily wheezing were associated with worse HRQOL (also measured by SGRQ)28. Unfortunately, we have not collected any data on exacerbations during the study period.

Strengths and weaknesses
We managed to include 82 patients with GOLD stage IV COPD who experienced severe limitations in daily life. Despite their limitations, they were willing and capable to fill in questionnaires about their HRQOL and functional status every three months. There is a possibility that only patients with a more favourable health status were able to participate in this study, thus leaving out patients with lower quality of life. We have no indication that the patients we included in our study had a deviant health status from what is generally described in GOLD stage IV patients. But even if this were the case, it would mean that the results of our study would be biased towards more favourable outcomes. The decline in HRQOL and functional status would perhaps be even worse if we had failed to include patients with the least favourable health status. Since we had no control group, there is a possibility that our results over time are subject to some regression to the mean. However, by stratifying the scores at baseline, we were able to examine the results in different strata. These strata continued to describe the same patterns. For instance, the
mean in the low severity subgroup remains well below the means of the intermediate and high severity subgroups. This makes regression to the mean very unlikely.

The patients we recruited had an FEV1 of less than 30% of predicted, a marker for GOLD stage IV. Our study criteria did not include restrictions in how long patients already had an FEV1 of less than 30% of predicted. Entrance in the study was not marked by other additional special occasions like admission to hospital or start of long-term oxygen therapy. This resulted in a mixed study population including both patients who were recently diagnosed as stage IV, as well as patients who had already been in this stage for years. We accounted for this possible difference in disease severity by stratifying the patient population at baseline.

The HRQOL and functional status measurements we used in this study are self-report, written questionnaires and are – by definition – subjective measurements. The results show that the activity domain on the SGRQ was not appropriate for this population because the results on this domain showed a ceiling effect. Although we saw no such effect in any of the other domains of the SGRQ and GARS, the upper limits of the confidence intervals of the least favourable groups were close to the maximal scores. This may be an indication that these questionnaires are not capable of monitoring further deteriorations in health status in this particular group of patients. The validity of the SGRQ in the most severe patients has been questioned before, by the developer of the SGRQ himself29. We would therefore recommend further research into the construction of a more appropriate questionnaire that is capable of detecting small changes in health status in this severely impaired group of patients. Progress in this area is already made by the recent development of new HRQOL and ADL measures for use in this severe patient group, such as the LCADL30 and MRF-2831, although the latter is not designed for COPD patients specifically. Since qualitative studies have shown that patients in the end-stage of COPD report a continuous deterioration in health status17,18,32-34, it should be possible to also quantitatively identify the small deteriorations that the most severe patients perceive in their health status. This information may then be used to help health care professionals to detect deteriorations at an earlier stage and, ultimately, improve palliative care provision in end-stage COPD patients.

In conclusion, this study shows that patients with advanced COPD experience low health-related quality of life and functional status for a long period of time. Deterioration in health status over time is mostly seen in the group of patients who entered the study with a more favourable health status, although it is expected that also the more severe patients
experience a deterioration, even though this could not be measured accurately. 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.
Acknowledgements
The authors would like to thank all participating patients and doctors for their time and efforts.

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Chapter 5

The silence of patients with end-stage COPD: a qualitative study

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Het zwijgen van patiënten in het eindstadium van COPD

Huisarts en Wetenschap 2009; 52: 527–532
Abstract

Background
Patients with end-stage chronic obstructive pulmonary disease (COPD) experience poor quality of life and considerable problems in daily life. However, as they often do not actively express a wish for help, they do not get the help they need.

Aim
To gain insight into why patients with end-stage COPD tend not to express a wish for help.

Design of study
Prospective qualitative study with semi-structured interviews.

Setting
Outpatient clinics of four hospitals and one centre specialising in asthma and COPD in the Netherlands.

Method
Sixteen semi-structured interviews were conducted with 11 patients with end-stage COPD.

Results
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 of their illness, 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.

Conclusion
Patients with end-stage COPD do not actively express a wish for help because they do not consider their limitations to be abnormal and because they do not realise that there are possibilities to improve their situation. These results suggest that care in this stage of the disease 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. Future research should focus on studying whether such an approach applies to the needs of patients with end-stage COPD.
Introduction
End-stage chronic obstructive pulmonary disease (COPD) follows a typical illness trajectory of long-term limitations with intermittent serious episodes, as described by Murray et al. Patients with end-stage COPD are usually ill for a long period of time with occasional acute exacerbations. Although these exacerbations are severe and may result in death, patients usually survive many such episodes. Studies in patients with end-stage COPD have shown that many experience poor quality of life and considerable problems in daily life. Most problems arise from breathlessness as this often leads to immobility, dependency on others, and social isolation. Anxiety and depression are also common. It could be expected that patients with such impairments have numerous preferences, wants, and demands regarding how their situation could be improved. However, as part of a larger study on care for patients with end-stage COPD using in-depth interviews with patients, indications were found that patients did not actively express a wish for help, even though they experienced numerous limitations in their daily lives: they remained silent. To gain insight into this silence, the current study’s research question was: ‘Why do patients with end-stage COPD not actively express a wish for help?’

Methods

Setting and participants
Responders were identified from a sample of patients with COPD collected for a previous quantitative study that employed written quality-of-life questionnaires in 2004–2006 in the Netherlands. In that study, 82 patients with Global Initiative for Chronic Obstructive Lung Disease (GOLD) stage IV (defined as forced expiratory volume in 1 second <30% of predicted) COPD who were aged 60 years or older were recruited randomly from outpatient clinics of four participating hospitals and one centre specialising in asthma and COPD in the Netherlands. Patients received a quality-of-life questionnaire every 3 months, for a maximum period of 1 year in total. From those 82 patients with end-stage COPD, 11 responders were selected for the present qualitative study. The sampling was done purposefully to ensure that a wide variety of patients’ experiences was recorded. A mix of male and female patients, patients living alone and living with their partner, and patients with and without long-term oxygen therapy were selected. Patients were included until data about the lack of expressed wish for help reached saturation. All patients provided informed consent.
**Interviews**

Semi-structured in-depth interviews were performed by one researcher at each patient’s home and lasted 1.5–2.5 hours. The aim of the interviews was to provide an in-depth viewpoint based on personal experience. This was done by using open-ended questions that were guided by a list of topics such as activities of daily living, medical and informal care, social support, stigmatisation, anxiety, and future. The interview process was iterative and the topic list evolved over time. For example, help-seeking behaviour was initially not one of the topics on the list, but was added after conducting the first few interviews, when it became apparent that patients did not actively express their wishes for help. The first question in every interview was: ‘Can you describe a normal day?’. All interviews were audio-taped and fully transcribed.

**Data analysis**

The analyses were done by two researchers using MAXQDA (VERBI software, Berlin) and consisted of multiple phases largely based on Pope et al.’s recommendations for qualitative research\(^{13}\). To get a feeling of what the patients had said about the topics, one researcher worked through the interviews deductively using the primary topic list (the familiarisation phase). After this, the analyses continued in a more inductive way to include other aspects, such as living with physical limitations and the relationship with others, as these subjects were frequently mentioned by the patients. Recurrent themes within the transcripts were then identified and text fragments were sorted. Discussion between all authors led to the arrangement of categories and themes. As a result, a thematic framework was constructed, consisting of categories and themes, as shown in Figure 5.1.

**Figure 5.1. Thematic framework**

- Physical limitations
- Adaptation
- Age / generation
- Acceptance
- Support from social environment

- Health care system
- Information provision
- Specialised health care

- Regarding oneself as ill
- Strategy to deal with activities: Avoiding / modifying
- Help seeking behaviour
- Options for improvement
Results
In total, 16 interviews with 11 patients were conducted by a researcher during a period of 2 years (2004–2006). Five patients were interviewed again after 6 months; for example because the first interview did not cover all topics from the topic list, or because something changed in the patient’s situation. It was possible to monitor patients’ progress because of the longitudinal aspect of the original study, in which patients received a questionnaire every 3 months. Patient characteristics are highlighted in Table 5.1; all patient names are fictitious.

**Table 5.1. Patient characteristics**

<table>
<thead>
<tr>
<th>Code name</th>
<th>Age, years</th>
<th>Sex</th>
<th>Marital status</th>
<th>Dependent on oxygen</th>
<th>Number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anton</td>
<td>70</td>
<td>Male</td>
<td>Married</td>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Ben</td>
<td>74</td>
<td>Male</td>
<td>Married</td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Charlotte</td>
<td>81</td>
<td>Female</td>
<td>Single</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Debby</td>
<td>61</td>
<td>Female</td>
<td>Married</td>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Edward</td>
<td>72</td>
<td>Male</td>
<td>Widowed</td>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Fiona</td>
<td>72</td>
<td>Female</td>
<td>Widowed</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Gerard</td>
<td>64</td>
<td>Male</td>
<td>Married</td>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>Harry</td>
<td>74</td>
<td>Male</td>
<td>Single</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Ian</td>
<td>65</td>
<td>Male</td>
<td>Married</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>John</td>
<td>83</td>
<td>Male</td>
<td>Married</td>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>Kevin</td>
<td>69</td>
<td>Male</td>
<td>Married</td>
<td>No</td>
<td>1</td>
</tr>
</tbody>
</table>

**Experienced limitations**
Before gaining an understanding of the silence of patients with end-stage COPD, the nature of the limitations they experience in daily life must be considered, as discussed in the interviews. Breathlessness was the most apparent physical limitation:

John: ‘I’m a lucky man whenever I wake up in the morning and I’m not breathless. When that happens, I stay in bed for a while to enjoy it. But only until I need to go to the toilet. That’s where the trouble starts, where the first breathlessness starts. After I’m finished, I come back to the bedroom and take oxygen for about 10 minutes.’
Anxiety was also common. Patients described that it is scary when they are unable to get control of their breathing. Sometimes, when they experienced severe breathlessness, they were afraid they would suffocate:

Gerard: ‘I’m not afraid of anything, except for suffocation. I’ve experienced the beginning of suffocation twice, and I really don’t want that to be my ending!’

Kevin: ‘When you get breathless, that’s not ... that’s not pleasant you know. I used to say “I’d rather spend a week in jail than spend one day in hospital”. That’s what I used to say, but now ... I’ve been taken to hospital three times by ambulance because I was breathless. And when that happens, you’re glad that they take you to hospital!’

Social limitations became evident when patients became less mobile as a result of their physical limitations. Sometimes, they did not leave their house for months, especially during winter because of bad weather conditions. Another reason mentioned was the increased risk of catching a cold that might turn into pneumonia.

Ian’s partner: ‘In summer he can go out and sit in the garden for a bit, but in winter, it’s mostly indoors.’

Anton: ‘Last winter, I didn’t go out at all.’

**Coping strategies**

To cope with their limitations, patients appeared to adopt one of two strategies:

- **Strategy 1:**
  to continue doing daily activities by modifying them; for example, taking breaks in between activities, or using aids and appliances. This enabled patients to keep up their physical condition and allowed them to spend time outside the house, which are necessary to maintain independence and a certain degree of social life.

- **Strategy 2:**
  to avoid activities altogether, instead of finding new ways to continue doing the activities they were used to.
Some responders used strategy 1, but most responders avoided activities:

Debby: ‘After the laundry was done, I used to hang it up immediately. I just put everything on the ground, and I had to bend over a lot. Now, I put the laundry basket on top of something else so I don’t have to bend over so much.’ (strategy 1)

Anton: ‘I would like to be able to go to the shopping mall, but that takes so much energy, so much energy, that it would have to be really necessary. Otherwise, I don’t go there.’
Interviewer: ‘Your life is really here, at home?’
Anton: ‘Yes.’ (strategy 2)

Ian: ‘We used to go walking a lot. We just can’t do it anymore because after about 100 metres I get out of breath. So, we don’t do it anymore. There’s no joy in that anymore.’ (strategy 2)

John: ‘If I’m honest, I have to say that I live in that chair for 99% of the time.’ (strategy 2)

When patients stop being active, they tend to become more and more dependent on people in their close environment for their daily functioning. However, even those who spent most of their time inside their house still did not actively seek help.

Conditions for asking for help
To be able to ask for help, as is often required for healthcare provision in modern medicine, two conditions have to be met:

- patients need to regard the limitations they experience as something out of the ordinary and a reason to go and seek help; and
- patients need to know that their situation may be improved.

From these interviews it became clear that both conditions were not met in most cases.
‘I have COPD but, apart from that, I am not ill’

The first condition to be able to ask for help was that patients needed to regard their limitations as abnormal. However, many of the patients interviewed did not feel that having limitations was the same as being ill. They appeared to consider themselves ill at a time of acute exacerbation of their illness, like an infection, or at any time when they were in hospital, but regarded their everyday life as normal:

Gerard: ‘We’re not really ill. It may sound funny, but a COPD patient is not ill. He is breathless. Whenever I get an infection, a bacterium, then I’m ill. But like now, I’m not ill because I can eat properly, I can still laugh, I still have fun in my life.’

Three reasons for not seeing oneself as ill were identified from the interviews. Patients with COPD spend a relatively long time in the end-stage of their illness, compared with illnesses with a different disease trajectory such as cancer. They adapt to their deteriorating health status because they have time to adjust to relatively small deteriorations and time to become used to their limitations. As a result, a life with limitations becomes normal:

Ian’s partner: ‘It just goes so slowly. We don’t really notice but other people do. They see that he can no longer do things that he could a year ago. For us it’s just normal.’

In addition to adapting to their limitations, patients compared themselves to other people of their own age. They found that most people their age had one or more chronic illness and used some kind of medication. Therefore, in comparison with others, patients with end-stage COPD regarded their limitations as an unavoidable part of ageing, instead of something unusual or undesirable.

Charlotte: ‘These lungs won’t get any better. That’s something you need to accept. Well, compared to other people...everyone has got something at my age! I feel lucky to have what I have.’

The way patients were viewed by others appeared to contribute to the way they perceived their limitations as something to live with, instead of something to seek help for. As their illness affects the lungs, it is less visible; as such, although they experience
limitations, people in their environment fail to recognise that they are suffering from an illness. Without recognition and encouragement from their environment, patients did not feel that what they had was something to seek help for. On occasion, they even experienced negative reactions from their environment:

Anton: ‘It’s hard to explain. Sometimes, I am working in the garden without any problems. After a while, I come into the house and boom, it’s over. Suddenly I’m exhausted, I can’t do anything. That’s hard to explain. She [my wife] sometimes doesn’t understand. But I don’t even understand! Because one moment, I’m working and the next, I can’t do anything anymore. It’s hard to explain because you can’t see any difference, I still look the same.’

The first condition that was needed for patients to be able to ask for help was not met; that is, patients did not regard the limitations they experienced as something out of the ordinary. The second condition, that patients should be aware that there are possibilities to improve their situation, was investigated.

‘I cannot be helped’

Patients in this study were seeing a respiratory physician on a regular basis, mostly once or twice a year. As well as these visits to the respiratory physician, they were all seeing their GP. However, as they were already seeing a specialist regarding these issues, they did not always discuss their lung problems with their GP:

Interviewer: ‘Is your GP involved in the care for your lungs?’
Anton: ‘No. I’m seeing a respiratory physician …’

Ian: ‘I visit the respiratory physician once a year, and when I’m really ill I go and see my GP. But that can be about something completely different. We don’t discuss my emphysema then. It’s registered somewhere, emphysema, but we don’t talk about it.’

The extent to which patients know or expect that their situation can be improved is dependent on the information they get regarding possible treatments. During the interviews patients explained that their conversations with the respiratory physician were mostly about the condition of their lungs. Patients said they were told that their lungs would only get worse, and that they would have to deal with that. More importantly, they
were told there was nothing more the respiratory physician could do for them. Patients often talked about their illness in these same terms:

Ian: ‘Well, the X-rays were good. I don’t know what good means, but eh, well, something that’s broke cannot be fixed. At least not with lungs.’

Patients lived with the assumption that, as their lungs were damaged beyond repair, they could not get help, and stated that both they and their physicians failed to discuss the limitations experienced in daily life and how these might be improved. It is likely that when doctors discuss daily activities with their patients, they would probably advise patients to be more active; however, because breathlessness increases with activity, being more active may feel scary for patients. Such advice would, therefore, not automatically improve the situation. According to the responders, despite their wondering about the course of the illness and what they could expect for the future, these issues were also hardly ever discussed with their physician. As a result, they drew their own conclusions, which were not always optimistic:

Kevin: ‘I make calculations. Before, my lung function was 35%, and 2 years later it was 5% less. So, I calculate a loss of 5% every 2 years. That means that after 4 or 5 years, grandpa will be gone.’

Patients with end-stage COPD believed that they could not be helped; as such, the second condition of asking for help was not met. In other words, patients were not aware that there are possibilities to improve their situation.

Discussion

Summary of main findings

The patients with end-stage COPD in this study experienced numerous limitations in their everyday lives. They did not always succeed in keeping up their daily activities, and sometimes avoided certain activities when these became too burdensome. Despite this, they did not actively express a wish for help because they did not regard their limitations as abnormal and they did not realise that there are possibilities to improve their situation.
**Strengths and limitations of the study**

This study adds to the limited body of knowledge about the end stage of COPD and the way patients experience their illness. The qualitative method used in this study is important for exploring patients’ experiences, opinions, and their daily lives. The possibility to return to the patient for further information is another strength of the study. Some difficulties were encountered in conducting the interviews because some patients had difficulties expressing themselves verbally. They sometimes had trouble in verbalizing their wishes and desires, even when they were directly asked to do so. However, this method proved valid as it was possible to extract the reasons for the absence of expressed wishes and desires, also described as the silence of the COPD patients. A limitation of the study is that, even though data saturation was reached concerning the lack of expressed wish for help, the researchers cannot be completely sure that in a different group of patients exactly the same results would be found. Therefore, a replication of this study is warranted to see whether the current results are found elsewhere. If so, a follow-up quantitative study is needed to explore the actual percentage of patients in this stage that fail to request any help.

**Comparison with existing literature**

Although the body of literature about the end stage of COPD is limited, there are publications that have reported on the poor quality of life experienced by patients in this stage\textsuperscript{14,15}. Studies report on the severe physical symptoms patients experience (mostly breathlessness)\textsuperscript{6,8,9,16}, and also on psychological and social symptoms, such as anxiety\textsuperscript{6,9,16}, depression\textsuperscript{6,9,16}, and social isolation\textsuperscript{8,17}. Jones et al\textsuperscript{5} also reported that many patients would not express needs even when prompted. This is consistent with the current findings that patients do not know that there are options to improve their situation. The authors suggested that this might be related to an unwillingness to appear ungrateful. The current findings further elaborate on and analyse this silence of patients who have COPD. Others have reported similar findings about help-seeking behaviour in people who have other chronic illnesses associated with older age. Sanders et al reported that patients with chronic arthritis, who had experienced pain and disability for decades, perceived their symptoms as being inevitable and associated with normal ageing. They were also pessimistic about formal care\textsuperscript{18}. Pound et al explored why older patients responded to a stroke as something that was ‘not that bad’ within the theory of biographical disruption\textsuperscript{19}. This is consistent with the current findings that patients do not consider themselves to be
ill. In a literature review, Koch described that very few women with urinary incontinence seek help. She found that, among other factors, the belief that urinary incontinence is a normal result of ageing affected help-seeking behaviour\textsuperscript{20}.

**Implications for clinical practice and future research**

Although there is consensus that patients with end-stage COPD have impaired quality of life, they do not receive appropriate help from healthcare institutions. Results of this study indicate that patients experience problems in conducting their daily activities. However, this study also indicates that these problems are rarely discussed with the treating physician (GP or respiratory physician). Therefore, it may be assumed that the care of patients with end-stage COPD should focus on improving activities of daily living instead of only aiming to improve lung function. Supporting and teaching care focusing on daily life is already applied by physical therapists in pulmonary rehabilitation programmes, which have proved to be successful even in patients with very severe COPD\textsuperscript{21,22}. As well as offering advice, this care actively supports patients in learning to keep up their daily activities by teaching them how to use breathing techniques, how to dose their energy, and how to use appropriate aids and appliances. The current study’s results suggest that patients with end-stage COPD may benefit from this type of supporting care focusing on daily life. Healthcare providers should actively explore what practical help these patients might welcome in sustaining normal daily activity. Future research should aim to study whether such an approach meets the needs of patients with end-stage COPD.
Acknowledgements
The authors would like to thank all patients who participated in this research for their time and efforts.

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Chapter 6

Coaching in end-stage COPD: improving palliative care provision by using the metaphor of athletics

Jolanda M. Habraken, Myra C. B. van Zwieten, Els J. M. Weersink and Dick L. Willems

Submitted for publication
Abstract

Background
In discussions about the palliative care provision for patients with end-stage COPD, hardly any attention is being paid to supporting patients in living as actively as possible until death. We aim to address this aspect of palliative care. The research question is: To what extent can the concept of patient work be used in describing the palliative phase of COPD, and in which way can this concept be used to improve palliative care provision?

Methods
Using a nested mixed methods design, patients enrolled in a former quantitative study were interviewed about their illness experiences. A primary inductive analysis of the research material, focussing 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.

Results
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 are. Likewise, health care professionals involved in caring for COPD patients may be compared to coaches.

Conclusions
We recommend a supportive coaching approach in end-stage COPD. The position of the coach – right next to the patient – enables a tailor-made approach. The coaching approach should be introduced early in the disease trajectory to avoid problems in the timing of the palliative phase and to prevent unnecessary loss of activity level and physical condition in later stages.
Introduction

Chronic Obstructive Pulmonary Disease (COPD) is one of the most important causes of morbidity and mortality in the western world\(^1\). Palliative care has historically focused on cancer disease trajectories, and specialised services for patients with a non-malignant disease like COPD are still in a developing stage\(^2-4\). Several studies have shown that patients in the end-stage of COPD do not have similar access to specific palliative care services when compared to patients suffering from advanced lung cancer\(^5-7\). One of the most important difficulties in providing high quality palliative care to patients with advanced COPD is the highly unpredictable disease trajectory. Prognoses for individual patients with COPD are described to be inaccurate\(^3,8\). However, it is increasingly recognised that patients with advanced COPD may benefit from the provision of the palliative care approach\(^9,10\) because they suffer from poor symptom control\(^11\), especially breathlessness\(^6,9,12-14\), anxiety\(^13-15\) and depression\(^13,14,16\) which often leads to social isolation\(^9\), increased dependency on others\(^17\) and poor quality of life\(^5,18\).

In palliative care, the main focus is on improving the quality of life of patients and their families during the final stages of life\(^19\). The palliative care approach is holistic and targets physical, psychological, social and spiritual dimensions\(^20\). According to the World Health Organisation, one of the aspects of palliative care is that it should support patients in living as actively as possible until death\(^19\). However, in discussions about palliative care provision, hardly any attention is being paid to this aspect. As a first start, Willems et al. show how much work patients with advanced heart failure need to perform in order to live with their illness and remain active\(^21\). They state that when caregivers have an understanding of the work patients have to perform to achieve mobility and activity, they may be more able to help patients live as actively as possible until death. The aim of the current paper is to better understand how the concept of patient work can improve the provision of palliative care in COPD. The research question is: To what extent can the concept of patient work be used in describing the palliative phase of COPD, and in which way can this concept be used to improve palliative care provision?

Methods

Setting and participants

Using a nested mixed methods design, patients with end-stage COPD were collected from a sample of 82 COPD patients with GOLD stage IV (defined as FEV1 < 30% of predicted), and age 60 years or older who participated in a quantitative study measuring their quality
of life\textsuperscript{22}. These 82 patients were recruited from outpatient clinics of four participating hospitals and one centre specialising in asthma and COPD in the Netherlands. Data collection took place in the period 2004-2006. Eleven patients from this quantitative sample were approached for an interview about their illness experiences\textsuperscript{23}. The sampling was done purposefully to ensure a mix of male and female patients, patients living alone and living with their partner, and patients with and without long-term oxygen therapy. Five patients were interviewed twice with a 6 months interval, for example because the first interview did not cover all topics from the topic list, or because something changed in the patient’s situation. We were able to monitor these changes in patients’ situations because of the longitudinal aspect of the original study, in which patients received a questionnaire every three months. All patients provided informed consent.

\textbf{Interviews}

Semi-structured in-depth interviews were performed by one researcher (JH) at the patients’ homes and lasted 1.5 – 2.5 hours. The aim of the interviews was to provide an in-depth perspective on personal experience with living with COPD. This was done by using open-ended questions that were guided by a topic list that contained, amongst other things, questions about activities in daily life. The interview process consisted of a repeated cycle of interviewing, transcribing, analysing and adjusting the topic list. The first question in every interview was: ‘can you describe a normal day?’ All interviews were audio-taped and fully transcribed.

\textbf{Data-analysis}

To familiarise with the research material\textsuperscript{24}, all transcripts were first read by the first author and a selection was read by MvZ. The analysis continued by structuring the material, in a deductive way, focussing on patient work. A software programme for analyzing qualitative data, MaxQda, was used for this purpose\textsuperscript{25}. The first analysis was done by the first author and checked by MvZ. Further steps in the analysis were discussed among all authors. After the first familiarisation phase, the analysis continued in an inductive way and focussed on how patients managed to live their daily life and on the problems they encounter in doing so. We identified situations in which patients did not succeed in keeping up their daily activities. We analysed these situations and compared them to situations in which patients did succeed in keeping up daily activities. Comparisons of these successful and unsuccessful situations led to the identification of enhancing and limiting factors.
Analysing these factors lead to the metaphor of athletics. From there, we worked backwards and described patient experiences in line with this metaphor which we used as our final analytical framework.

**Analytical framework**

Four categories can apply to athletics in general (loosely based on a tactical games approach\(^{26}\): prerequisites, skilfulness, tactics and mentality. By using these categories as our analytical framework, we describe the skills that COPD patients need in order to be able to live with their illness. We describe these skills in analogy of the skills that are necessary for sports(wo)men to become successful in athletics.

**Metaphor of athletics**

It may seem awkward to compare patients in the end-stage of COPD to athletes, but living with advanced COPD is often described by patients themselves as a continuous struggle because getting enough air is extremely hard work for them. Besides, this is work that never stops. In athletics, sports(wo)men are keen to improve their skills in order to reach some kind of achievement. The nature of this achievement may differ according to the level of the sports(wo)man. For beginners, their goal may be to reach a higher level of playing, or entering a prestigious tournament. For professional athletes, the goal may be to win a gold medal at the Olympics. For patients with end-stage COPD, the goal they are trying to achieve is not to win a gold medal, nor to achieve something extraordinary. Mostly, their goal is to maintain a certain level of daily activities.

Respondent nr 30: ‘I get by. Let’s put it that way. But I wouldn’t say that I have a fantastic life. Because I don’t. They’ve just repaved the market square, but I haven’t been out there to see it yet. Because I cannot get there, it’s too far!’

Interviewer: ‘What would you consider to be a fantastic life?’

Respondent: ‘Well, if I could walk one kilometre. Just one kilometre, for the entire day. So that I could walk to the supermarket, or the pharmacist, and back. That’s all I want. But I can’t do it, I really can’t. When I leave the house here, there’s a bench on the next corner and when I get there, I really need to sit down. If I want to walk to the supermarket, I need to sit down four times before I get there! And that’s not even a kilometre away.’
Results
In total, 16 interviews with 11 patients were conducted by the first author (JH) during a period of 2 years (2004-2006). See Table 6.1 for patient characteristics and lung function.

Table 6.1. *Patient characteristics and lung function*

<table>
<thead>
<tr>
<th>Patient number</th>
<th>Age</th>
<th>Sex</th>
<th>Marital status</th>
<th>Oxygen dependent</th>
<th>Number of interviews</th>
<th>FEV1 L (% pred)</th>
<th>BMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>70</td>
<td>Male</td>
<td>Married</td>
<td>No</td>
<td>2</td>
<td>0.86 (28)</td>
<td>21</td>
</tr>
<tr>
<td>17</td>
<td>74</td>
<td>Male</td>
<td>Married</td>
<td>Yes</td>
<td>1</td>
<td>0.75 (29)</td>
<td>20</td>
</tr>
<tr>
<td>22</td>
<td>81</td>
<td>Female</td>
<td>Single</td>
<td>No</td>
<td>1</td>
<td>0.52 (27)</td>
<td>25</td>
</tr>
<tr>
<td>23</td>
<td>61</td>
<td>Female</td>
<td>Married</td>
<td>No</td>
<td>2</td>
<td>0.67 (29)</td>
<td>24</td>
</tr>
<tr>
<td>30</td>
<td>72</td>
<td>Male</td>
<td>Widowed</td>
<td>No</td>
<td>2</td>
<td>0.83 (25)</td>
<td>23</td>
</tr>
<tr>
<td>38</td>
<td>72</td>
<td>Female</td>
<td>Widowed</td>
<td>No</td>
<td>1</td>
<td>0.66 (30)</td>
<td>28</td>
</tr>
<tr>
<td>50</td>
<td>64</td>
<td>Male</td>
<td>Married</td>
<td>Yes</td>
<td>2</td>
<td>0.75 (23)</td>
<td>19</td>
</tr>
<tr>
<td>54</td>
<td>74</td>
<td>Male</td>
<td>Single</td>
<td>No</td>
<td>1</td>
<td>0.89 (28)</td>
<td>33</td>
</tr>
<tr>
<td>59</td>
<td>65</td>
<td>Male</td>
<td>Married</td>
<td>No</td>
<td>1</td>
<td>0.95 (29)</td>
<td>26</td>
</tr>
<tr>
<td>60</td>
<td>83</td>
<td>Male</td>
<td>Married</td>
<td>Yes</td>
<td>2</td>
<td>0.69 (22)</td>
<td>21</td>
</tr>
<tr>
<td>70</td>
<td>69</td>
<td>Male</td>
<td>Married</td>
<td>No</td>
<td>1</td>
<td>0.85 (28)</td>
<td>27</td>
</tr>
</tbody>
</table>

To be able to live with a slowly progressive disease like COPD requires a lot of practice, experience and perseverance. Adaptation to deteriorating health is an ongoing process that requires skills such as flexibility and creativity23. Where athletes are trying to improve their achievements to become more successful in athletics, patients with end-stage COPD are trying to maintain their level of daily functioning despite their deteriorating health. In their case, the level of achievement they are trying to reach stays the same while the efforts they have to make in order to reach this same level will increase as their illness progresses. In both cases, the level of strain and effort increases over time. Table 6.2 summarises the key components of sports in athletics and COPD that we used in our analysis.
Table 6.2.  **Athletics and COPD compared**

<table>
<thead>
<tr>
<th></th>
<th>Athletics</th>
<th>COPD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prerequisites</strong></td>
<td>A place to play sports, such as a tennis court or a swimming pool</td>
<td>Accessibility of public places, aids and appliances such as stair lift or parking places for the physically disabled</td>
</tr>
<tr>
<td><strong>Skilfulness</strong></td>
<td>Training to improve personal skills and to recognise own strengths and weaknesses</td>
<td>Training to improve breathing techniques and physical condition and to recognise exacerbations</td>
</tr>
<tr>
<td><strong>Tactics</strong></td>
<td>Identifying optimal training schedule in order to perform optimally at the right time</td>
<td>Setting appropriate goals and dosing energy</td>
</tr>
<tr>
<td><strong>Mentality</strong></td>
<td>To stay motivated, learning how to perform under pressure</td>
<td>Maintaining a positive attitude, developing perseverance and dealing with emotions</td>
</tr>
</tbody>
</table>

**Prerequisites**

An athlete needs some basic facilities, such as proper material and an appropriate location for playing that particular sport. Likewise, for a COPD patient, some basic conditions will have to be met in order for the patient to be able to live his or her everyday life. Because of their severe physical limitations, it is important for patients to have access to appropriate aids and appliances that enable them to maintain their daily life. Walking aids like a motorised wheelchair or a stair lift are basic facilities that may help patients to keep up their daily activities. Facilities that stimulate accessibility of public places like parking places for the physically disabled or public benches – like the ones respondent number 30 uses to go to the supermarket – are examples of prerequisites that a COPD patient in the end-stage needs in order to be able to conduct basic daily activities. Still, patients talk about how these prerequisites are not always available. Respondent number 59 talks about the parking problems he encounters at the hospital.

Respondent nr 59: ‘I have a parking permit for the physically disabled. But still, at the hospital, there’s never any parking space. Never’.
These parking problems make it extremely difficult for him to get to his lung physician in time when he has to park his car further away from the entrance. However, by being creative, he has solved this problem himself.

‘I rescheduled my appointments from winter to summer. Now, I have my annual appointment in June. That’s much better because in June I can go to the hospital by moped, instead of by car. I can park it right outside the emergency room so I can walk from there to my lung physician in only one go.’

Skilfulness
To become successful in athletics, developing skills is most important. Most sports(wo)men begin playing their favourite sport out of interest in the game. If they want to improve their achievements, they will have to practise. Patients with end-stage COPD also need to develop skills in order to be able to improve their achievements. Patients learn to deal with their deteriorating health by trial and error. There is no one to teach them the necessary skills to overcome the limitations they encounter, caused by their symptoms. They develop their own expertise, like respondents 17 and 50.

Respondent nr 17: ‘When I want to walk up the stairs, it takes me about 10 minutes. It’s only 15 steps! When you (interviewer) would do it, it would only take you half a second. And my brain wants to do it more quickly too, because my brain knows it’s only 15 steps. But if I do it more quickly, I get myself into trouble. Because then, when I get upstairs, I really cannot get any air at all. And that’s terrifying! You know that, you learn that. So that’s why I don’t do it in 5 minutes, but I do it in 10’.

Respondent nr 50: ‘When I’m out of breath, I always sit in a particular way, like King Kong, with my arms spread wide open! That works for me, although I don’t know if it will also work for someone else. But I have a lot of experience of course, and good results. I also do it in hospital, and sometimes I see other patients looking at me funny’.

Tactics
When the sports(wo)man has achieved a certain level by developing technical skills, tactical decisions need to be made in order to be able to perform at the right time. A tailor made, optimal training schedule needs to be set up to ensure he or she will be in optimal
form at just the right time. The balance between training, strain, gain and focus is a
delicate one. Likewise, in patients with end-stage COPD, developing technical skills is
important, but not always enough to reach their goals. When patients have learnt the best
way to catch their breath, this is usually only the first step in order to reach their goal,
such as walking to the supermarket like respondent number 30. To be able to do that,
tactical decisions need to be made, with regard to balancing training, strain, gain and
focus. One of the most important tactical skills that patients need in reaching their goals,
is to dose their energy in such a way that they can perform at just the right moment. If a
desired goal is to walk to the supermarket, this goal will not be met if getting up in the
morning and getting washed and dressed takes up so much energy that the patient is
confined to a chair for the rest of the day. Respondent number 23 describes how she is so
tired in the evening that she cannot attend the course she intended to follow.

Respondent nr 23: ‘My husband is from Egypt. And I always had the intention to learn
Arabic once I was retired. So I started an evening course, but I can’t keep it up. In the
evening, I’m just too tired. So I gave up that study’.

Another aspect of tactical skills is to set appropriate goals. Sometimes, patients set goals
for themselves that are not realistic given their physical condition. Patients may then end
up frustrated and angry. Otherwise, patients may set goals that are too low. That way,
they are least confronted with their limitations. However, this may result in a physical
condition which is worse than it could be because of lack of exercise.

*Frustration*

Respondent nr 11: ‘What I used to do in one day takes me two, three days now. Everything
is different now. They don’t have to ask me for help with anything, because every
movement is difficult for me. Every movement takes space and time. If I move, it’s
impossible to repeat that movement right away. And that’s hard. You have to learn to live
with that, but that’s really hard’.

Respondent nr 30: ‘I’m not worth anything anymore! I used to trade in old furniture, I went
to houses when the people who had been living there had died and I would buy all the
furniture. I would have three of those places empty in just one day. And now I am moving
house myself, and it takes me three days just to pack a few boxes. That’s my problem’.
**Low goals**

Respondent nr 60: ‘I feel that I gave up physical exercise too easily. I used to do some exercises on the treadmill and I still drove my car. But then, when I had to have oxygen 24 hours a day, it all became much more difficult. To go out with oxygen you know. I had to call the people I was visiting in advance to ask them to help me getting out of the car with my bottles of oxygen. So, I stopped doing that. But now, I feel that I have gotten worse sooner than I expected. For example, going to the toilet is a real challenge. And to get from here to the kitchen and back, that seems like a huge distance although it is only ten steps.’

**Mentality**

When athletes have developed technical and tactical skills, and the prerequisites are met, another major influence in winning or losing the match is the mental component, which includes skills such as positive thinking, ambition and perseverance. Also for patients with end-stage COPD, the mental component is crucial in reaching the desired goal. It is important to maintain a positive attitude. Ambition and perseverance are important characteristics for achieving goals.

Respondent nr 38: ‘There aren’t many activities I had to give up because of my lungs, because I always keep on trying to do things. And sometimes I hit my nose while trying, but I always try first. Only if I really can’t do something anymore, then I accept it and think “Well, that’s too bad”.’

Respondent nr 30: ‘I always cook my own food. Even when I’ve had a terrible day, I still do it! Because I think that eating healthy is very important. That’s why I do it, despite everything’.

Respondent nr 50: ‘I always see the point in going on. Yes, sometimes all my energy is gone, that’s true. But the next day I will be busy in building up new energy to do what I want. Because I want to leave the house with my wife, so I have to get new energy’.

While patients report that they do have a positive outlook and do not give up easily, they also report about the fear that breathlessness induces, and which limits them in their daily activities.
Respondent nr 60: ‘I hope to improve my condition so I can walk a bit further. But, you know, it is also often psychological. Because of fear, you know. When you get breathless somewhere, then you feel it every time you pass that same point. That’s typical’.

Discussion

As an answer to the first part of our research question, “To what extent can the concept of patient work be used in describing the palliative phase of COPD?”, this study shows that living with end-stage COPD may be compared to sports(wo)men trying to improve their skills in athletics. 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 sports(wo)men do.

Coaching

In which way can these findings be used to improve palliative care provision? Patients are able to develop many skills by themselves. However, just like sports(wo)man 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 be beneficial for COPD patients in all four categories of our analytical framework.

First of all, a coach would be the appropriate person for a COPD patient to address problems in accessibility and other prerequisites for conducting daily activities. Secondly, a coach could help patients in developing the right technical skills. The coach would have to be an expert in techniques that improve breathing and physical condition and provide targeted training. The coach could support patients in their own creativity to deal with symptoms, but could also act as the provider of information and knowledge about best practices for patients with less creativity or less understanding of how their own body reacts to the illness.

Thirdly, in tactics, one of the most important tasks of the COPD coach would be to design a tailor made training program to help the patients dosing their energy and to make sure the energy the patient puts into the training program results in maximal gain. The coach should also indentify the personal possibilities of each patient, and support patients in choosing their goals appropriately. Most importantly, the coach needs to have a clear
vision of the overall picture in order to support and guide patients appropriately. This overall picture is essential to be able to initiate targeted interventions when necessary. In athletics, a coach can involve external help like a masseur to recover from a muscle injury. In COPD, the coach overlooking the overall picture can also initiate external help where appropriate, such as a physical therapist to improve physical condition or a dietician for dietary advice.

Fourthly, the last important task would be to encourage positive mental characteristics of patients and to address fear of breathlessness and other emotional aspects of the illness such as talking about death and dying. The importance of psychosocial care should in no way be underestimated in this group of patients, since a positive mentality can increase performance but the opposite can also occur.

In summary, the coaching approach we recommend is a holistic, multidisciplinary type of care. The COPD coach will be able to provide shoulder to shoulder care, supportive in nature. This is in line with the definition of palliative care by the World Health Organisation, including the emphasis on staying as active as possible until death. The position of the coach – right next to the patient – enables a tailor-made approach. By introducing the coaching approach early in the disease trajectory, problems concerning the timing of the palliative phase and the prognosis of death become less relevant because the coach can modify the training programme to each individual patient from the onset of the illness onwards. This also has the advantage that 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. The coaching approach can therefore be seen as a continuum for each COPD patient uniquely, which will fluctuate according to the patient’s preference.

A well-known intervention in COPD care that also provides care in a holistic and multidisciplinary matter is pulmonary rehabilitation. Pulmonary rehabilitation programmes are proved to be effective in improving dyspnea, exercise tolerance, functional capacity and health-related quality of life, also in patients with advanced COPD. However, pulmonary rehabilitation is not a part of usual care and is therefore only accessible for a few COPD patients, despite international recommendations. Besides, these programmes have a fixed duration and sufficient follow up is usually not provided. The coaching approach we recommend in this paper will therefore need to be integrated into regular general care.
This study provides a new perspective on the provision of palliative care in patients with end-stage COPD, building on the concept of ‘patient work’\textsuperscript{32}. Our study has a small sample of 16 interviews with 11 patients. Still, the sampling was done purposefully to ensure a variety in male and female patients, patients living alone and living with their partner, and patients with and without long-term oxygen therapy. Besides, we have no reason to assume that our sample is deviant from most COPD patients in the end-stage. Most importantly, the data we generated from these 11 patients proved to be rich enough to enable us to develop the fruitful concept of the COPD coach.

We are aware that not all patient experiences that we came across during the interviews, could be fitted into the metaphor of athletics. For example, patients often describe how they encounter difficulties in daily life because they suffer from an illness that is invisible to others\textsuperscript{23}. While this is an important aspect of the illness experience of patients with end-stage COPD, we could not fit it into our metaphor of athletics. Our aim however was not to develop a metaphor in order to describe all aspects of end-stage COPD, but to propose an alternative way of looking at health care provision for this group of patients.

In conclusion, we believe that the image of a COPD coach is a powerful concept that can help to improve palliative care provision to the vulnerable group of end-stage COPD patients towards a more tailor-made, supportive and multidisciplinary type of care.


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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\(^{10}\). According to Bradshaw, when two groups of patients with similar characteristics are compared, and only one of those two group 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\(^ {11}\). 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’ 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. 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. 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\(^{16,17}\). The forced expiratory volume in one second (FEV\(_1\)) is most often used as an indicator for disease severity and for predicting mortality\(^{18}\). 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\(^{19}\). 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\(^{19}\), exacerbations\(^{20}\) and health-related quality of life\(^{21}\) 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\(^{34}\). 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\(^{35}\) and MRF-28\(^{36}\). 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


**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, focussing 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.
**Samenvatting**

COPD, Chronic Obstructive Pulmonary Disease, is een chronische progressieve aandoening van de longen, die een dodelijke afloop kan hebben. Wereldwijd gezien is COPD één van de meest voorkomende doodsoorzaken. Terwijl het bekend is dat COPD patiënten een kortere levensverwachting hebben dan gezonde mensen blijkt het toch moeilijk om de prognose voor individuele patiënten nauwkeurig te voorspellen. Dit komt door het onvoorspelbare ziektepad van COPD in het eindstadium. Er is ook nog weinig bekend over de problemen waar COPD patiënten in het eindstadium tegenaan lopen. Dit alles maakt de verlening van hoogstaande palliatieve zorg aan deze patiënten problematisch. Het algemene doel van deze studie was daarom om de problemen, behoeften en voorkeuren van COPD patiënten in het eindstadium in kaart te brengen en beter te begrijpen.

In de algemene inleiding, beschreven in **hoofdstuk 1**, wordt allereerst een kort overzicht gegeven van relevante achtergrondinformatie. Er wordt beschreven hoe de palliatieve zorg zich heeft ontwikkeld. Oorspronkelijk richtte deze zorg zich uitsluitend op kankerpatiënten, maar tegenwoordig is het een allesomvattende vorm van zorg die zo vroeg mogelijk toegepast zou moeten worden in elk ziektepad dat uiteindelijk de dood tot gevolg heeft, inclusief COPD. Drie verschillende ziektepads aan het einde van het leven worden beschreven, en er wordt algemene informatie gegeven over COPD. Het hoofdstuk eindigt met de onderzoeksvragen van de studie: Wat is er bekend over de zorgbehoeften van COPD patiënten in het eindstadium? Op welke gebieden ontbreekt kennis nog? Hoe is de kwaliteit van leven van COPD patiënten in het eindstadium vergeleken met longkankerpatiënten in het eindstadium? Hoe verandert de kwaliteit van leven en de functionele status van COPD patiënten in het eindstadium gedurende de tijd? Hoe uiten COPD patiënten in het eindstadium hun zorgbehoeften? In hoeverre kan een beter begrip van het eindstadium van COPD gebruikt worden om palliatieve zorgverlening te verbeteren?

In **hoofdstuk 2** wordt een gestructureerde literatuurstudie gepresenteerd. Het doel hiervan was een overzicht te geven van de relevante literatuur op het gebied van zorgbehoeften van COPD patiënten in het eindstadium en te bekijken op welke gebieden kennis nog ontbreekt. Om onze resultaten te structureren hebben we gebruik gemaakt van een classificatiesysteem van zorgbehoeften, ontwikkeld door Bradshaw. Dit classificatiesysteem maakt onderscheid tussen vier verschillende typen van
zorgbehoeften: normatieve behoefte, gevoelde behoefte, geuite behoefte en vergelijkende behoefte. Zevenenzeventig publicaties werden gevonden waarvan er tien werden geïncludeerd in de studie. De resultaten uit de geïncludeerde artikelen beschreven een breed scala aan onderwerpen, die allemaal werden gepresenteerd als zorgbehoeften. De meeste resultaten gingen over ‘gevoelde behoefte’. Dit zijn behoeften die patiënten zelf hebben genoemd. Resultaten over ‘normatieve behoefte’ (gebaseerd op het oordeel van experts) ontbrak. We concluderen dat de literatuur over zorgbehoeften van COPD patiënten in het eindstadium Schaars is, en dat er geen algemeen geaccepteerde definitie bestaat van zorgbehoeften. Als we kijken naar de groeiende vraag naar zorg voor COPD patiënten in het eindstadium, dan is er duidelijke behoefte aan meer onderzoek naar dit onderwerp.

Als een eerste stap naar meer kennis over dit onderwerp, hebben we de kwaliteit van leven gemeten van COPD patiënten in het eindstadium. Om te onderzoeken of COPD patiënten dezelfde of een ergere last ervaren van hun ziekte werden COPD patiënten vergeleken met longkankerpatiënten in eenzelfde ziektestadium. Dit wordt beschreven in hoofdstuk 3. Tweeëntachtig COPD patiënten en negentien longkankerpatiënten vulden generieke en ziektespecifieke kwaliteit van leven vragenlijsten in. Behalve het vergelijken van de kwaliteit van leven van deze twee patiëntengroepen, hebben we ook een meta-analyse uitgevoerd met individuele patiëntgegevens. Deze gegevens waren afkomstig van een belangrijke studie op dit gebied, gepubliceerd door Gore et al. in 2000. Ook hebben we een sensitiviteitsanalyse uitgevoerd met een subgroep van patiënten die binnen een jaar na het begin van de studie waren overleden. We hebben verschillen gevonden in kwaliteit van leven tussen COPD en longkankerpatiënten op het gebied van lichamelijk functioneren, sociaal functioneren, geestelijke gezondheid, algemene gezondheidspercepties, kortademigheid, dagelijkse activiteiten en depressie. De kwaliteit van leven van COPD patiënten was consistent slechter dan die van longkankerpatiënten. De sensitiviteitsanalyse, met daarin alleen de patiënten die echt terminaal waren, bevestigde deze resultaten. We concluderen dat COPD patiënten in het eindstadium hun kwaliteit van leven als slechter ervaren, vergelijkbaar met of zelfs erger dan longkankerpatiënten dat doen. Dit is een indicatie dat COPD patiënten een vergelijkbare behoefte hebben aan palliatieve zorg.

Deze tweeëntachtig COPD patiënten hebben de vragenlijsten (SGRQ en GARS voor het meten van kwaliteit van leven en functionele status, respectievelijk) een jaar lang elke drie maanden een keer ingevuld. We wilden hiermee de veranderingen in kwaliteit van leven
en functionele status in de tijd in kaart brengen. De resultaten hiervan worden besproken in **hoofdstuk 4**. De gegevens werden g-analyseerd door de studiepopulatie te stratificeren in subgroepen van ernst. Deze subgroepen werden ingedeeld op basis van het laagste, middelste en hoogste tertië van de SGRQ en GARS scores aan het begin van de studie (baseline meting). Statistische modellen (mixed models) werden gebruikt voor het voorspellen van het verloop van de SGRQ en GARS in de tijd. De kans op overleving werd bekeken met behulp van Kaplan-Meier curves en univariate Cox proportional hazards modellen. Het beloop van kwaliteit van leven en functionele status liet een geleidelijke afname zien in de tijd. De voorspelde afname van SGRQ en GARS scores na één jaar (duidelijk een verslechtering van gezondheidstoestand) was het grootst in de minst ernstige subgroepen. We concluderen dat COPD patiënten in het eindstadium hun kwaliteit van leven en functionele status als slecht ervaren en dat dit langzaamaan nog verder afneemt in de tijd. Zelfs de patiënten die tijdens de studie zijn overleden, rapporteerden geen plotselinge achteruitgang in kwaliteit van leven. Dit geeft aan dat voor het beter in kaart brengen van het eindstadium van COPD, clinici niet veel extra houvast hebben aan het afnemen van de SGRQ en GARS.

In **hoofdstuk 5** worden de resultaten besproken van zestien interviews met elf COPD patiënten in het eindstadium; een subgroep van de patiënten die beschreven werden in hoofdstuk 3 en 4. De patiënten werden geïnterviewd over hun ziekte-ervaringen. Tijdens de interviews werd duidelijk dat patiënten terughoudend waren met het actief om hulp vragen. Dit ondanks de ernstige problemen die ze tegenkwamen in het doen van hun dagelijkse activiteiten. We wilden dit fenomeen beter begrijpen. De resultaten geven aan dat patiënten hun beperkingen moeten beschouwen als iets abnormaals, en dat ze zich zouden moeten realiseren dat er mogelijkheden voorhanden zijn om hun situatie te verbeteren, voordat ze actief om hulp kunnen vragen. Dit was echter niet het geval bij de patiënten die we hebben geïnterviewd. Patiënten bleken zichzelf alleen te beschouwen als ziek wanneer er sprake was van een acute exacerbatie. Ze beschouwden hun dagelijks leven als normaal. Ze waren daarbij ook in de veronderstelling dat ze niet geholpen konden worden, aangezien hun longen zover kapot waren dat er toch niks meer aan te doen was. Uit deze resultaten volgt dat ze zorg voor COPD patiënten in dit stadium zich zou moeten richten op het verbeteren van het dagelijks leven, in plaats van zich uitsluitend te richten op het verbeteren van de longfunctie. Zorgverleners zouden bij individuele patiënten op een actieve manier moeten nagaan bij welke vorm van praktische hulp zij het meest gebaat zouden zijn bij het in stand houden van hun dagelijkse activiteiten.
Om zorgverleners nog meer specifieke handvatten te kunnen geven voor het verbeteren van de zorg voor COPD patiënten in het eindstadium, hebben we ons meer toegeespitst op het werk dat patiënten zelf doen om hun dagelijkse activiteiten zoveel mogelijk in stand te houden. Dit wordt beschreven in hoofdstuk 6. In een primair inductieve analyse hebben we specifiek gekeken naar situaties waarin patiënten er wel of juist niet in slaagden om hun dagelijkse activiteiten in stand te houden. Dit leidde tot de sportmetafoor die we vervolgens hebben gebruikt als analytisch kader voor de analyse van het interviewmateriaal. Leven met COPD in het eindstadium kan worden vergeleken met sporters die hun prestaties proberen te verbeteren. Allereerst moet er aan bepaalde randvoorwaarden worden voldaan. Daarna kunnen COPD patiënten vaardigheden ontwikkelen in techniek, tactiek en mentaliteit op eenzelfde manier als sporters dat doen. Volgens dezelfde vergelijking zouden zorgverleners vergeleken kunnen worden met sportcoaches. We bevelen daarom ook een coachende benadering aan in het eindstadium van COPD. De positie van deze coach – naast de patiënt – maakt een op maat gemaakte aanpak mogelijk.

In hoofdstuk 7, de algemene discussie, wordt een samenvatting gegeven van de belangrijkste bevindingen van de studie. Daarna volgt een reflectie op deze bevindingen en op de onderzoeksmethoden. Het hoofdstuk eindigt met aanbevelingen voor verder onderzoek en met implicaties voor de klinische praktijk. De belangrijkste conclusies zijn dat COPD patiënten in het eindstadium een grote ziektebelasting ervaren op fysiek, psychologisch en sociaal gebied. Dit verdient onze aandacht omdat het eindstadium van COPD jaren kan duren. Een nuttige, nieuwe benadering voor zorgverleners om achter de problemen, behoeften en voorkeuren van COPD patiënten in het eindstadium te komen, zou specifieke aandacht voor dagelijkse activiteiten kunnen zijn en voor opgedane ervaring door de patiënt zelf. Om de palliatieve zorg principes te implementeren op een manier waarop de focus zoveel mogelijk ligt op het actief houden van patiënten, maar waarbij – tegelijkertijd – de palliatieve zorg visie niet verloren gaat, bevelen we een coachende benadering aan, vergelijkbaar met sportcoaches. Door deze coachende benadering al vroeg in het ziekteproces te implementeren worden problemen met het bepalen van het begin van de palliatieve fase en de prognose van overlijden minder relevant. Patiënten leren bovendien veel eerder in hun ziekteproces vaardigheden aan zodat inactiviteit en conditieverlies zoveel mogelijk voorkomen kunnen worden.
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About the author

Jolanda Habraken (1976) graduated in 2000 in Biomedical Health Sciences at the Radboud University Nijmegen. She obtained her Masters degree in both Epidemiology and Evaluation of Health Care.

After graduation, she worked at the Department of Social Health Care of the Erasmus University in Rotterdam for two years. She worked on the evaluation of the national screening program for cervical cancer. In this function, she could combine both specializations of her Masters.

After this, she worked at the Netherlands institute for health services research (NIVEL) in Utrecht for a year, evaluating a special fund for GPs working in socially deprived areas in the Netherlands. In this position, she first got acquainted with qualitative research methods and with the interesting topic of vulnerable people.

In 2003, she started working at the Academic Medical Center in Amsterdam, at the Department of General Practice. The results of this research are described in this thesis. During this research project, she once again focused on a vulnerable group of people, and specialized further in qualitative research methods by conducting qualitative research herself (as well as quantitative research) and by participating in the AMC Network for Qualitative Health Research (currently called AMcKOG).

From November 2008, she is working at the Academic Research Centre for Health and Social Care (Tranzo) at Tilburg University. As an action-researcher, she is working on the evaluation of a project that aims to enhance the participation of vulnerable people in four areas in the province of Noord-Brabant, the Netherlands. In this project, she combines her interest for research methodology and vulnerable people.
Over de auteur


Na het behalen van haar doctoraal kreeg zij een functie bij het Instituut Maatschappelijke Gezondheidszorg aan de Erasmus Universiteit in Rotterdam waarin haar twee afstudeerrichtingen goed konden worden gecombineerd. Zij werkte binnen deze functie aan de evaluatie van het bevolkingsonderzoek naar baarmoederhalskanker.

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In 2003 is zij begonnen met haar promotieonderzoek aan de afdeling Huisartsgeneeskunde van het Academisch Medisch Centrum in Amsterdam. De resultaten van dit onderzoek zijn beschreven in dit proefschrift. Tijdens dit promotietraject heeft zij zich wederom verdiept in een kwetsbare groep, en heeft zij zich verder kunnen bekwamen in kwalitatieve onderzoeksmethoden door zelf (naast kwantitatief onderzoek) kwalitatief onderzoek uit te voeren, en door actief deel te nemen aan het Netwerk Kwalitatief Onderzoek van het AMC (tegenwoordig AMcKOG).

Vanaf november 2008 is zij werkzaam bij het Wetenschappelijk Centrum voor Zorg en Welzijn (Tranzo) aan de Universiteit van Tilburg. Zij werkt daar als actieonderzoeker aan de evaluatie van een ontwikkeltraject dat de maatschappelijke participatie van kwetsbare burgers in vier wijken in Noord-Brabant tracht te bevorderen. In dit project combineert zij haar interesse voor onderzoeksmethodologie en kwetsbare doelgroepen.