Palliative care needs of patients with advanced COPD: an exploration of illness experiences
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Chapter 3

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

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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{1-3}. However, it is increasingly recognized that palliative care may be the most appropriate approach for patients in the terminal stages of any illness\textsuperscript{4}. 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{5}. 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{6-12}. 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>2.21* (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
*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$^{a,b}$

<table>
<thead>
<tr>
<th>Patient group</th>
<th>Physical functioning</th>
<th>Role physical</th>
<th>Bodily pain</th>
<th>General health perceptions</th>
<th>Vitality</th>
<th>Social functioning</th>
<th>Role emotional</th>
<th>Mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD n=82</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
</tr>
<tr>
<td></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>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>(IQR)</td>
</tr>
<tr>
<td>COPD: n=82</td>
<td>6</td>
<td>(3-10)</td>
</tr>
<tr>
<td>NSCLC: n=19</td>
<td>7</td>
<td>(4-10)</td>
</tr>
<tr>
<td>P-value</td>
<td>0.641</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 (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
</tr>
<tr>
<td>COPD: n=82</td>
<td>18 (15-22)</td>
<td>16 (13-19)</td>
<td>34 (29-41)</td>
</tr>
<tr>
<td>NSCLC: n=19</td>
<td>12 (11-17)</td>
<td>12 (9-17)</td>
<td>25 (20-35)</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.14 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>82</td>
</tr>
<tr>
<td></td>
<td>Gore et al.</td>
<td>50</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>69.5 (6.7)</td>
<td>70.5 (5.5)</td>
</tr>
<tr>
<td>Male n (%)</td>
<td>54 (66)</td>
<td>22 (44)</td>
</tr>
<tr>
<td>Female n (%)</td>
<td>28 (34)</td>
<td>28 (56)</td>
</tr>
<tr>
<td>FEV1 (SD)</td>
<td>0.68 (0.2)</td>
<td>0.52 (0.2)</td>
</tr>
</tbody>
</table>

*SD = standard deviation

*a Based 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.
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\(^{14,15}\): 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\(^{6-12}\). 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. 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, 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, including those in The Netherlands. Although women are increasingly being diagnosed with COPD, and historically, there may have been gender bias in the diagnostic process, COPD prevalence rates are generally higher in males. 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., we have selected a more diverse COPD group, including more stable patients (in line with Hill and Meurs’ recommendation). 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. 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


(31) 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.

