How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer

J M Gore, C J Brophy, M A Greenstone

Abstract

Background—Patients with severe chronic obstructive pulmonary disease (COPD) have a poor quality of life and limited life expectancy. This study examined whether these patients were relatively disadvantaged in terms of medical and social care compared with a group with inoperable lung cancer.

Methods—An open two group comparison was made of 50 patients with severe COPD (forced expiratory volume in one second (FEV1) <0.75 l and at least one admission for hypercapnic respiratory failure) and 50 patients with unresectable non-small cell lung cancer (NSCLC). A multi-method design was used involving standardised quality of life tools, semi-structured interviews, and review of documentation.

Results—The patients with COPD had significantly worse activities of daily living and physical, social, and emotional functioning than the patients with NSCLC (p<0.05). The Hospital Anxiety and Depression Scale (HADS) scores suggested that 90% of patients with COPD suffered clinically relevant anxiety or depression compared with 52% of patients with NSCLC. Patients were generally satisfied with the medical care received, but only 4% in each group were formally assessed or treated for mental health problems. With regard to social support, the main difference between the groups was that, while 30% of patients with NSCLC received help from specialist palliative care services, none of the patients with COPD had access to a similar system of specialist care. Finally, patients in both groups reported a lack of information from professionals regarding diagnosis, prognosis and social support, although patients' information needs were disparate and often conflicting.

Conclusion—This study suggests that patients with end stage COPD have significantly impaired quality of life and emotional well being which may not be as well met as those of patients with lung cancer, nor do they receive holistic care appropriate to their needs. (Thorax 2000;55:1000–1006)

Keywords: chronic obstructive pulmonary disease; lung cancer; quality of life; depression; palliative care
described as the active total care of patients whose disease is incurable and where the control of physical, psychological, social, and spiritual problems is paramount. Although many patients might benefit from such an all embracing beneficence, the reality of its practical delivery is almost exclusively confined to malignant disease.8 Palliative care is not synonymous with terminal care and it should be apparent that the palliative approach—centring on symptom management, maintenance of a reasonable quality of life, good communication, and practical and emotional support for carers—is necessary for a range of chronic debilitating illnesses and should routinely be an integral part of their management. Although this philosophy has recently been embraced by those dealing with AIDS and degenerative neurological disorders, there is still a huge unmet potential for patients suffering from end stage cardiac9 and respiratory diseases.10

Respiratory physicians in the UK spend much of their professional lives looking after patients with COPD and lung cancer, usually in the same hospital setting and with the support of the same medical and nursing teams. Nevertheless, our impression was that, among the population of COPD patients who required frequent admission to hospital, the care was unsatisfactory; some patients appeared to have a disproportionately lengthy stay or were readmitted without clear objective signs of deterioration. Others presented in extremis, necessitating rushed decisions about intubation with little information available about their previous quality of life or wishes about resuscitation. Patients with lung cancer, however, seemed to enjoy a more holistic and integrated package of care. We hypothesised that the COPD population might have an equally poor health status, be dissatisfied with their level of care, and have similar palliative needs to the lung cancer population, but that these needs were not recognised or met. We set out to measure their quality of life, psychological morbidity, satisfaction with care (particularly in relation to communication with medical and social professionals), and provision of practical assistance. We aimed to compare the effectiveness in meeting the care needs of both groups. To do this we used a mixture of sociometric and psychological tools, plus in-depth interviews using qualitative techniques frequently employed in social research. To our knowledge this is the first time these groups have been compared in this way.

Methods

PATIONS

We studied 50 patients with severe COPD (forced expiratory volume in one second (FEV1) <0.75 l and at least one admission for hypercapnic respiratory failure) and 50 patients with inoperable non-small cell lung cancer (NSCLC). None of the patients with NSCLC were receiving radiotherapy or chemotherapy at the time of interview and none were thought to have significant airflow obstruction. Patients with COPD were identified from outpatient records of patients attending for follow up at Hull chest clinic. In the NSCLC group about one third were attending Hull chest clinic and the rest were identified from the database of the department of radiotherapy (that is, most patients had been referred for and received palliative radiotherapy). The lower age limit was 60 years. Written informed consent was obtained from all patients. The study was approved by the Hull and East Riding Research ethics committee. Patients were interviewed in their own homes by a single interviewer (JG). At the time of interview patients performed spirometric tests (Microspirometer MicroPlus, Micromedical Ltd, UK).

QUALITY OF LIFE INSTRUMENTS

In order to measure disease specific health status we used validated disease specific quality of life (QoL) tools. Patients with COPD were asked to complete the St George’s Respiratory Questionnaire (SGRQ)11 and patients with NSCLC were given the EORTC Core QoL Questionnaire (QLQ-C30) and Lung Cancer Supplement (QLQ-LC13).12 Both groups were also assessed using generic health related QoL tools: the MOS Short Form-36 Health Survey (SF-36)13; the Nottingham Extended Activities and Daily Living (EADL) Scale14; and the Hospital Anxiety and Depression Scale (HADS).15 The SF-36 has been used in many cancer studies16 and has been validated in COPD.17 In addition, it has been proved to be robust for the comparison of patients with different conditions in a variety of settings.18 The EADL has been used in patients with severe COPD19 but not in cancer patients. The HADS does not rely on the presence of somatic symptoms which may characterise physical illness, and is therefore a valid global assessment of psychological morbidity in hospital patients.15 20

ASSESSMENT OF MEDICAL/SOCIAL CARE

A semi-structured interview was designed to ascertain the views of patients regarding the quantity and quality of medical and social care received and the amount of information they had been given on their disease and treatment. Patients were asked to grade their satisfaction on a categorical scale of 1–7 where 7 represented “extremely satisfied” and 1 “extremely dissatisfied”. General practice and hospital documentation were used to help verify the self-reported data from 20 patients chosen randomly from each group, particularly in relation to medication, aids and appliances, and social support.

ANALYSIS OF DATA

The interview data were coded and, with the QoL data, analysed using the Statistical Package for the Social Sciences (SPSS). All data were visually analysed. Parametric data were analysed by analysis of variance (ANOVA) and non-parametric data by the Wilcoxon signed rank test and Mann-Whitney U test. Qualitative data were scrutinised using social research techniques including categori-
Forced expiratory volume in one second (FEV1) and Karnofsky Performance Index (KPI) were used to help define the groups. KPI scale 0–100: a score of 50–80 indicates severe disability with a lower score indicating worsening performance. *Mann-Whitney U test.

### Table 1 Mean (SD) demographic characteristics of the patient populations

<table>
<thead>
<tr>
<th></th>
<th>COPD</th>
<th>NSCLC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>70.5 (5.5)</td>
<td>71.4 (6.5)</td>
</tr>
<tr>
<td>M/F (%)</td>
<td>44/56</td>
<td>72/28</td>
</tr>
<tr>
<td>FEV1 (l)</td>
<td>0.52 (0.17) (n=49)</td>
<td>1.47 (0.39) (n=42)</td>
</tr>
<tr>
<td>p&lt;0.0001</td>
<td>p=0.436</td>
<td></td>
</tr>
<tr>
<td>KPI</td>
<td>62.5 (10.4)</td>
<td>66.9 (9.2)</td>
</tr>
<tr>
<td>p&lt;0.05*</td>
<td>p&lt;0.05</td>
<td></td>
</tr>
</tbody>
</table>

Forced expiratory volume in one second (FEV1) and Karnofsky Performance Index (KPI) were used to help define the groups. KPI scale 0–100: a score of 50–80 indicates severe disability with a lower score indicating worsening performance. *Mann-Whitney U test.

### Table 2 Depression subscale of Health Anxiety and Depression Scale (HADS) for the two groups

<table>
<thead>
<tr>
<th></th>
<th>COPD</th>
<th>NSCLC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>10.18 (3.95)</td>
<td>7.22 (5.16)</td>
</tr>
<tr>
<td>Range</td>
<td>3–21</td>
<td>0–20</td>
</tr>
<tr>
<td>Scale</td>
<td>0–21</td>
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</table>

### Table 3 Anxiety subscale of the Hospital Anxiety and Depression Scale for the two groups

<table>
<thead>
<tr>
<th></th>
<th>COPD</th>
<th>NSCLC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>11.44 (4.76)</td>
<td>7.20 (5.25)</td>
</tr>
<tr>
<td>Range</td>
<td>1–20</td>
<td>0–21</td>
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<tr>
<td>Scale</td>
<td>0–21</td>
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### Quality of Life Data

#### Disease specific questionnaires

The SGRQ has four domains: symptoms, impacts, activities, and a total score. It rates health status as a percentage, a higher score indicating a worse QoL. The mean (SD) SGRQ scores for the COPD group were: symptoms 80 (14%); impacts 85 (13%); total 72 (14%). The EORTC has three main “functioning” categories (physical, social, and emotional) and a global score. A higher score (as a percentage) indicates a better QoL. The mean (SD) scores for patients with NSCLC were: physical 42 (23%); social 53 (35%); emotional 70 (30%); global 45 (27%).

#### Generic questionnaires

The EADL has a scale of 0–22, a lower score representing greater limitation. The COPD group had a significantly worse mean (SD) EADL score than the NSCLC group (9.4 (4.1) vs 11.3 (4.2), p<0.05). For all the dimensions of the SF-36 questionnaire apart from roles physical and emotional, patients with COPD had significantly worse (lower) mean scores than those with NSCLC (fig 1). Similarly, the HADS scores were significantly worse (higher) in the COPD group than in the NSCLC group, with the mean scores reaching a level suggesting clinically relevant disease in the former but not the latter group (tables 2 and 3).

In addition, the interview data revealed that 82% of patients with COPD were housebound compared with 36% of those with NSCLC, and 36% and 10%, respectively, were largely chairbound (only able to move from one room to another with great difficulty). Furthermore, while most of the patients with NSCLC felt able to accept their illness and retain a fairly positive outlook, most of the patients with COPD were “frustrated”, “angry”, and expressed anxiety about attacks of dyspnoea.
MEDICAL CARE

The mean numbers of outpatient attendances were similar in both groups (table 4); 80% of patients with NSCLC had received palliative radiotherapy in the previous 12 months, accounting for most of their outpatient visits. Almost all of the outpatient attendances in the COPD group were follow up visits to the chest clinic. However, the numbers of emergency admissions and GP visits per year differed between the groups, with the COPD patients having significantly more emergency admissions per year (largely due to exacerbations) and the NSCLC patients seeing their GP more often (usually because of newly emerging symptoms). The most commonly used medications in the COPD group were bronchodilators (94%), long term oxygen therapy (LTOT) (40%), and inhaled or oral steroids (38%). In the NSCLC group opiate analgesia (36%) was the most commonly used medication. Although 90% of patients with COPD and 52% of those with NSCLC had scores suggesting depression or anxiety, only 4% in each group received further assessment and treatment.

The majority of patients in both groups (86% COPD, 84% NSCLC) were generally satisfied with the quantity of medical care and attention received. The level of satisfaction with medical care (measured by a seven point rating scale) did not differ between the groups, with mean (SD) scores of 5.9 (1.4) and 5.7 (1.4) in the COPD and NSCLC groups, respectively. These scores approximated to the response “very satisfied”. However, in the interviews most patients in both groups qualified their satisfaction rating by stating that 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.

| Table 4  Mean (SD) number of outpatient follow up visits, emergency admissions, and GP visits per year |
|-----------------|-----------------|-----------------|
|                 | Outpatient follow up visits | Emergency admissions | GP visits |
| COPD            | 3.2 (1.3)        | 4.1 (4.0)        | 8.5 (6.8)  |
| NSCLC           | 5.2 (10.5)       | 1.3 (1.2)        | 10.7 (11.2) |
| p=0.2           | p<0.001          | p=0.01           |

INFORMATION PROVISION

A major area of dissatisfaction for patients in both groups was the perceived inadequate provision of information regarding their illness, its

Figure 2  Proportion of each group receiving various aids and appliances.
management, and the type of social help available. Thirty percent of COPD patients and 34% of NSCLC patients felt that diagnostic information had been lacking or given insensitively and 78% and 80%, respectively, said that they did not receive enough information regarding their prognosis or future management from their hospital doctors. In many cases the patients’ awareness of their prognosis was brought about through their own experiences—for example, emergency admissions—and through conversations with other health personnel such as district nurses. Some patients with COPD reported that, as they had received little information, they felt unprepared for their current poor state of health. Other patients with COPD complained that they had not understood the terms used by their doctors during initial consultations—for example, “emphysema” or “COPD”—nor their implications. In the NSCLC group the main area of concern was the absence of information regarding treatment. For example, some patients spoke of being “left in a vacuum” while doctors decided whether palliative radiotherapy was appropriate. A minority gave accounts of doctors contradicting one another with regard to illness management. Furthermore, some cancer patients felt that the initial diagnosis had been given insensitively or abruptly.

However, patients’ information needs were diverse and sometimes ambiguous and contradictory. Although 42% of patients with COPD and 40% with NSCLC suggested they wanted more information regarding their illness and future management at the time of interview, very few wanted detailed information and implied that an accurate description of their likely progression would be distressing (a typical comment being “what you don’t know can’t hurt you”). In the NSCLC group 24% were frustrated that the doctor had avoided the word “cancer” while 18% felt more comfortable with less fearful words such as “shadow” or “growth”. Many patients appeared to be in denial; while almost all of the patients in both groups knew that they had a life threatening illness, 42% with NSCLC and 26% with COPD said or implied that they did not know whether they would die from their disease. When asked why they did not request more information from their doctors, most patients stated that they felt it was inappropriate and that such discussions should be initiated by their specialists.

**Discussion**

Current best practice demands that patients with malignancy have access not only to oncological expertise to maximise survival prospects but also to a multidisciplinary palliative approach which focuses on how best to support patients and their families through the illness while maintaining reasonable quality of life. Key aspects include symptom control, recognition and management of psychological problems, good communication skills, and helping patients and carers with financial and practical issues. We postulated that patients with severe COPD might benefit from this approach and set out to compare their needs with those of a group of patients who were the traditional recipients of this type of holistic care. We confirmed that these severely ill patients with COPD had a very poor QoL in terms of emotional, social, and physical functioning and that there was a high prevalence of unrecognised psychological disorder and unmet information needs.

The groups were grossly similar in terms of their poor performance status as measured by the Karnofsky scale, although there was a small difference in favour of the NSCLC patients. The participants were drawn from different consultants’ case loads and uniformly satisfied the selection criteria. Further, their disease specific QoL scores were comparable with those of previously studied patients with the same diseases. Although we recognise that the patient populations might appear somewhat atypical, demographic characteristics did not affect the selection process nor the numbers who agreed to be interviewed. The sex distribution in the COPD group reflects the high local prevalence of this disease in women and East Riding Health Authority figures confirm the near equality of admission by sex for COPD (ICD-10 codes J40–44). The patients with NSCLC appeared to have a relatively lengthy survival from diagnosis. Although not explicitly excluded, we were reluctant to approach people who were rapidly deteriorating or were in the process of receiving treatment. In this group some patients had initially undergone what was thought to be curative surgery (and then relapsed) while many of the remainder were identified from department of radiotherapy records and were fit enough to have received and recovered from palliative treatment. Because of these factors many of the patients were in a relatively stable state at the time of interview. It is our contention that the patient population was a representative sample of patients with end stage COPD and longer surviving, but inoperable, NSCLC. Although the data are based on interviews with patients, GP and hospital documentation were used to help verify data acquired from a random sample of patients. Our scrutiny of medical records...
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such as fatigue, weight loss, and sleep disturbance and is refractory to treatment. Unfortunately, “reactive” psychological morbidity is an inevitable consequence of chronic physical disease and is refractory to treatment. Unfortunately, many of the biological symptoms of depression such as fatigue, weight loss, and sleep disturbance are common in advanced COPD and may well have been ascribed to the latter.

Information provision was inadequate in terms of both content and delivery. The deficiencies experienced by the patients in this study may be partly explained by the variation and complexity in patients’ information needs and, particularly in the NSCLC group, the likelihood that some might have been in denial. Patients described the seeking of reassurance and their disappointment when their doctors were unable to give it. Some wished they had received more information, irrespective of the distressing content, while others did not wish to know. In the former case it may be that the patients’ need for more detailed information conflicted with the doctors’ need to protect them and to retain an optimistic outlook. The complexity of patients’ information requirements and the demonstrated failure to meet them confirms the primacy of communication skills in everyday practice and the necessity of their refinement at all levels of seniority.

The paramount difference in care between the groups was in social and community support. Compared with the lung cancer group, the patients with COPD received more aids and appliances but, because of their greater physical limitation, this did not necessarily meet their needs and they were more likely to be dissatisfied with the care received. The most obvious disparity was that the patients with NSCLC had ready access to specialist palliative care services whereas those with COPD did not have an equivalent system of support. The patients with COPD experienced a lack of regular needs assessment at home and their palliative care requirements remained unrecognised. In some cases, however, the respiratory support nurse, working outside her usual remit, provided valuable practical help and advice. Two sets of guidelines have briefly considered the process of providing some form of pastoral support to patients with severe COPD in the community. Both advocate a respiratory health worker as the means to deliver advice on “psychosocial and respiratory problems and to improve compliance…” The optimum use of such personnel has yet to be defined and there is surprisingly little known about their usefulness. One controlled study of the impact of a respiratory health worker showed increased levels of patient knowledge and satisfaction and a trend to reduced mortality, but longer hospital stays and no reduction in admission rate. Current estimates suggest that there are fewer than 300 specialist respiratory nurses in the UK (C Fehrenbach, personal communication) and local priorities may be focused on other diseases such as asthma or tuberculosis. Given the prevalence of severe COPD in the community, these numbers are clearly inadequate.

In recent years pulmonary rehabilitation has been more widely introduced, usually in a secondary care setting. These programmes are variably constituted but are commonly multi-disciplinary and usually directed at those with at least moderately severe COPD. In addition to a physical training component, some form of

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psychological support is incorporated and many programmes have educational, social work, and occupational therapy inputs. Most studies suggest improvements in exercise tolerance, quality of life, and coping skills after completing treatment, but the benefits may not be sustained and the numbers of patients able to receive treatment at any one time may be limited for practical reasons. Both interventions appear to address some of the problems faced by patients with COPD, although the number of patients with the potential to benefit far exceeds capacity.

Are these results generalisable to the rest of the UK? There appear to be no available data on pastoral care for patients with COPD, but intuitively the picture is unlikely to be uniform and will depend on the local prevalence of other respiratory diseases, existing resources and, to a degree, the perceived priorities of secondary care and the health authority. The care of cancer patients is likely to depend on similar factors and also the proximity to a hospice or cancer centre and the nature of the community served. From our observations there is no reason to believe that our service is very different from that available elsewhere but, in order to test this, it would be necessary to repeat a similar study in another centre.

The COPD population we studied received a system of support which was fragmentary and largely dependent on initiatives from secondary care. While social care provision for the patients with NSCLC was suboptimal—for example, lack of information regarding social benefits and illness management—these patients had the safety net of a more holistic approach provided by a team with palliative care skills. The absence of a similar model for patients with COPD is partly historical, but the hospice movement is now beginning to recognise that the disability, progressive nature, and poor prognosis of such chronically ill patients makes them suitable candidates for this type of holistic care. Nevertheless, COPD does not appear to be regarded as a high profile illness by the public or health professionals. It is tempting to speculate that the common view of this condition as a self-inflicted disease and its lengthy time course have allowed it to be relegated in the hierarchy of areas for action and concern.

In conclusion, this study confirms our hypothesis that patients with end stage COPD have palliative care needs which remain unaddressed. We would argue that many of them have unmet information requirements, unrecognised psychological problems, a very poor overall QoL, and a need for palliative care which parallels that of patients with lung cancer. This study is a further contribution to the growing body of research which suggests that patients with end stage COPD require more holistic and patient centred care than they are currently receiving.

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