Thorax

Editorials

Palliative care for patients with non-malignant end stage respiratory disease

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Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality in the United Kingdom; 28 000 people in England and Wales died of the disease in 1999, a figure comparable with lung cancer which killed 29 000 people in the same year.[1] Equal numbers of patients with COPD and lung cancer are therefore experiencing preterminal disease and are likely to require similar medical and social services. The UK Department of Health's expert report published in 1992[2] advocated the extension of palliative care services to all who need them, whatever their diagnosis. Since then, the availability and provision of holistic supportive care to patients dying from non-malignant disease has become a topical issue for palliative medicine.[3] However, while countries such as the USA admit a high proportion of non-cancer patients to hospice inpatient units (30% in 1994–5),[4] the UK lags far behind, concentrating these services mainly on cancer patients with only a small proportion of hospice inpatients (4% in 1995) suffering from diseases other than cancer.[5]

Severe COPD and advanced lung cancer are both progressive diseases which are often managed by the same health care professionals such as primary care teams. However, the palliative care needs of patients with these two diseases have never previously been compared. The publication of the paper by Gore *et al* in this issue of *Thorax* is therefore of interest because it provides further evidence that the care needs of patients with severe COPD should be considered in the same way as those with lung cancer.[6] This is an important message for medical practice where the relevance of palliative care skills to patients with terminal non-malignant conditions is recognised but where the framework for extending these services beyond cancer patients is still in need of development.[7]

The aim of palliative care is the achievement of the best quality of life for patients and their families.[8] This aim is often assessed by measures of quality of life. The concept of quality of life, however, is complex and difficult to define, being both individual and multidimensional and, although many instruments exist which attempt to quantify it, measurement is difficult. In the medical context, quality of life is usually measured in terms of physical symptoms, psychological well being, and limitations on physical and social functioning. Thus, the majority of instruments in common use are health related quality of life (HRQoL) measures. Generic measures, which are applicable to anyone including those in good health, are useful for comparing diseases or for measuring disease related impairment by comparisons with data from "normal" populations. There is still some debate, however, about the applicability of generic instruments in chronic disease and the Medical Outcomes Study Short Form 36 (MOS SF-36), for example, has been shown to have limitations in some groups of patients.[9] Disease specific instruments, by comparison, have items relevant to the condition being studied. They are therefore more sensitive to change and can be used to measure outcomes and evaluate the effects of treatment or other interventions. The St George's Respiratory Questionnaire (SGRQ)[10] and the Chronic Respiratory Disease Questionnaire (CRDQ)[11] are examples of questionnaires frequently used in studies of respiratory patients to measure HRQoL. In studies of COPD these instruments have shown how interventions such as rehabilitation programmes and inhaled corticosteroids can improve quality of life for patients.[12 13] They have also provided evidence that, as the disease progresses, quality of life declines but, in common with generic measures, they do not always correlate strongly with objective measures of physical function such as forced expiratory volume in one second (FEV_1) in patients with COPD.[14] This reflects the fact that quality of life is not only a highly personal concept but also a dynamic one, changing as individuals adjust to changes in their health status and react to experience, interpersonal relationships, and altering roles.

In cancer studies the European Organisation for the Research and Treatment of Cancer Core questionnaire (EORTC QLQ-C30) and the site specific module LC-17 for lung cancer is a well validated and widely used outcome measure.[15] Many cancer studies now include HRQoL as an end point but sequential data for lung cancer are less common than for COPD as worsening symptoms and shorter survival times mean that drop out from studies is high. Some studies have reported longitudinal quality of life data for lung cancer patients using various instruments but these have mainly been concerned with demonstrating differences between treatment modalities.[16]

Gore *et al* propose that patients with COPD experience worse quality of life than those with lung cancer and that COPD care is less well resourced in the UK, despite the similar patterns of morbidity and mortality that both diseases produce. However, readers should be aware of the methodological limitations of this study which, while not entirely negating the conclusion, mean that some caution is needed in the interpretation of the results.

The sampling method used by the authors produced two study populations which are atypical in sex distribution and disease severity, and in length of survival in the lung cancer group. Of the 28 000 deaths from COPD in England and Wales in 1999, 56% were men and 44% were women. The male:female proportions were reversed in the study sample which, while it may be explained by local variations in the prevalence of COPD in men and women, is relevant here because the lung cancer group studied was biased toward male sex: 72% men/28% women compared with national figures of 62% and 38%, respectively. Health

surveys in random samples of the general population consistently report sex differences in physical symptom reporting, and female sex is associated with higher levels of symptomatology and lower self-reported health status.[17] Although this effect is not always seen in specific groups of cancer patients, it is relevant to the generic assessment of HRQoL. Women, both in cancer studies and in other diseases, also report higher anxiety levels measured by the Hospital Anxiety and Depression Scale (HADS).[18]

The medical criteria used for the selection of patients also have implications for the generalisability of the results. By selecting only COPD patients who had had at least one admission for hypercapnic respiratory failure, the authors may have excluded many more stable emphysematous patients with severe disease and an FEV_1 of less than 0.75 l. By intentionally identifying end stage COPD, they selected a group of very severely impaired patients whereas, in the cancer group, the median interval between diagnosis and interview of one year was twice the median survival time of about six months for patients with non-small cell lung cancer (NSCLC) in the UK. Thus, while not explicitly excluding patients with a poorer prognosis, failing to study a representative number of them has resulted in an atypical sample of patients with NSCLC.

The health related quality of life data presented in this paper gave generic and disease specific scores for two sample groups which showed the COPD group to be reporting worse quality of life on comparable dimensions. This is an important result, notwithstanding any reservations related to the study populations used, but the levels of impairment need to be placed in context in order to fully understand their meaning.

It is difficult to compare different studies of quality of life in lung cancer patients because of the large number of cancer specific instruments available to researchers and the various methods used to present the results. Gore *et al* commented that their patients reported disease specific scores comparable to those studied by Aaronson *et al* in 1993.[19] However, 90% of the patients in the study by Aaronson and coworkers had a good performance status (WHO grade 0–2) which is probably not typical of NSCLC overall. In comparison, a recent study of 65 patients in the Netherlands with a poorer performance status receiving palliative radiotherapy for previously untreated, locally advanced, or metastatic NSCLC reported lower EORTC scores for emotional function.[20] Similarly, the mean HADS scores are not easily comparable with other groups of NSCLC patients. Many authors opt for categorising HADS scores on the basis of "normal", "borderline", or "significant anxiety and depression" rather than quoting actual scores, while others present median scores and ranges which are appropriate summary statistics for this type of data.[21 22] However, we are aware of one paper which reported mean HADS scores for a random sample of 751 Norwegian inoperable or relapsed patients with a variety of cancers including lung cancer. Compared with this study, the patients studied by Gore *et al* appeared to score much better on the HADS scale. Although not directly comparable, the Norwegian patients are representative of those who would require palliative care services at some stage.[18]

Scores for the SGRQ range from 0 to 100 with higher scores representing a worse level of functioning. The mean (SD) total scores of 72 (14)% for the SGRQ support the view that these patients with COPD were experiencing very severe disease compared with those in other studies using the same instrument. The ISOLDE study[12] examined the effect of inhaled corticosteroids in 751 patients with moderate to severe COPD (FEV_1 50% of predicted normal and at least 0.8 l after bronchodilator) and reported baseline mean (SD) total scores of just under 50% for the SGRQ (placebo group, n = 375: 49.9 (17.4)%; treatment group, n = 376: 47.7 (17.6)%).

Effectively, Gore *et al* have compared long term survivors with long term sufferers; as not enough is known about the way individuals value the many aspects of quality of life—particularly in relation to illness—this comparison is not straightforward. The diagnosis of cancer is a devastating and emotive one but not all its impacts are persistently negative. Cancer patients have been shown, for example, to report more positive social experiences than a random sample of the population, possibly as a result of relatives and friends being brought closer together in a time of crisis.[23] Depression measured on the HADS scale has also been shown to lessen as the interval from the diagnosis of cancer increases.[18 24] In COPD the pattern is different; social isolation is common, as in many chronic and progressive diseases, as dependency increases and the burden of caring becomes harder for relatives and friends to cope with. HADS depression scores for patients with COPD mirror this, worsening as the disease progresses.[25] Gore *et al* may indeed have identified a real and important difference in the overall quality of life in these two patient groups, but their findings need to be confirmed in further studies, ideally including NSCLC patients undergoing active treatment or those who have been diagnosed with more advanced disease.

The proposal that patients with COPD are less well served by the UK health care system than those suffering from lung cancer is one that respiratory health care professionals would intuitively accept. However, a survey by the British Thoracic Society in 1997[26] showed that fewer than 30% of lung cancer units then had access to a specialist cancer nurse. The assumption that there are more specialist cancer nurses than respiratory nurse specialists with an interest in COPD may therefore be flawed. Cancer is a high profile disease associated with death, pain, and suffering which touches the lives of many and is perceived as being worse than most other diseases by the general population. There is no doubt that more counselling and palliative care services are available for cancer patients, many funded by charitable organisations and staffed by volunteers. Patients with severe COPD are often disabled by their disease for longer, and have a mortality rate comparable to that of many common cancers. COPD should therefore be viewed as a disease with similarities to cancer and there is no moral reason to exclude this group of patients from a palliative care approach including access to inpatient facilities and outreach services. There is already good evidence to show that outreach support such as local rehabilitation programmes for patients with COPD improves quality of life and that the benefits are sustained.[13] Palliative care professionals are already extending their services to patients with motor neurone disease and HIV/AIDS. Although further comparisons would be useful, this paper adds to the evidence that palliative care has a role in chronic and debilitating non-malignant diseases. As Archie Cochrane wrote in 1972: "Cure is rare but the need for care is widespread . . ".[27] In the case of chronic irreversible conditions like COPD this remains very true today.

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Management of malignant pleural effusions

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Malignant pleural effusion is a common problem in respiratory medicine and oncology and in some series accounts for up to 50% of all pleural effusions.[1 2] The median survival following diagnosis ranges from three to 12 months and is largely dependent upon the underlying malignancy. Currently, lung cancer is the most common metastatic tumour to the pleura in men and breast cancer in women. Both malignancies account for 50–65% of all malignant effusions while lymphomas, genitourinary, and gastrointestinal tumours account for a further 25%, and 7–15% of all malignant effusions have no identifiable primary.[3–5]

Malignant effusions result predominantly from obstruction and disruption of lymphatic channels by malignant cells. However, vascular endothelial growth factor (VEGF), a potent angiogenic mediator and promoter of endothelial permeability, is produced in significant amounts by diseased pleural tissue and is thought to play a part in the formation of malignant effusions and local tumour growth.[6 7]

The general approach to managing malignant effusions is determined by symptoms (dyspnoea, exercise tolerance limitation, and chest discomfort), performance status of the patient, expected survival, and response of the known primary tumour to systemic treatment. Intervention options range from observation in the case of asymptomatic effusions through simple thoracentesis to more invasive methods such as thoracoscopy, pleuroperitoneal shunting, and pleurectomy. Repeated aspiration is favoured in patients with limited survival and poor performance status and obviates lengthy hospitalisation. In the patient with reasonable survival expectancy and good performance status, every attempt should be made to prevent recurrence of the effusion. Intercostal tube drainage with instillation of a sclerosing agent, resulting in the obliteration of the pleural space, is the most widely used and cost effective method to control recurrent symptomatic malignant effusions.

Size of drainage tube

Over the last two decades several new developments have modified the method originally described by Adler and Sayek.[8] By convention, large bore intercostal tubes (size 24–32 F) have been used for drainage of malignant effusions and intrapleural administration of sclerosing agents. These large tubes are frequently associated with significant discomfort to patients and restrict mobility. Studies using small bore catheters (8–14 F) have reported similar success rates to those using large bore tubes, and small bore catheters are better tolerated and associated with less discomfort.[9–12] In the only controlled randomised study published to date, no significant difference was seen in the pleurodesis success rate but larger randomised studies are required to confirm these results.[13] A further potential advantage of the small bore catheter is in the area of ambulatory treatment of malignant effusions. Patz *et al*, using small bore catheters (10 F) and bleomycin as a sclerosing agent, achieved a modest pleurodesis success rate of 79% in outpatients.[14]

When to sclerose

Lung re-expansion remains the most important requisite for successful pleural symphysis and sclerotherapy failures usually occur when complete lung re-expansion is not