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Palliative care or end-of-life care in advanced chronic obstructive pulmonary disease

A prospective community survey

Abstract

Background
Calls for better end-of-life care for advanced chronic obstructive pulmonary disease (COPD) reflect the large number who die from the disease and their considerable unmet needs.

Aim
To determine palliative care needs in advanced COPD.

Design
Cross-sectional interview study in patients' homes using structured questionnaires generated from 44 south London general practices.

Method
One hundred and sixty-three (61% response) patients were interviewed, mean age 72 years, 50% female, with diagnosis of COPD and at least two of: forced expiratory volume in the first second (FEV_1) <40% predicted, hospital admissions or acute severe exacerbations with COPD, long-term oxygen therapy, cor pulmonale, use of oral steroids, and being housebound. Patients with advanced cancer, severe alcohol-related or mental health problems, or learning difficulties, were excluded; 145 patients were included in the analysis.

Results
One hundred and twenty-eight (88%) participants reported shortness of breath most days/every day, 45% were housebound, 75% had a carer. Medical records indicated that participants were at least as severe as non-participants. Eighty-two (57%) had severe breathlessness; 134 (92%) said breathlessness was their most important problem; 31 (21%) were on suboptimal treatment; 42 (30%) who were severely affected had not been admitted to hospital in the previous 2 years; 86 of 102 who had been admitted would want admission again if unwell to the same extent. None expressed existential concerns and few discussed need in terms of end-of-life care, despite severe breathlessness and impairment.

Conclusion
Needs in advanced COPD were considerable, with many reporting severe intractable breathlessness. Palliation of breathlessness was a priority, but discussion of need was seldom in terms of 'end-of-life care'.

Keywords
COPD; dyspnoea; epidemiology; palliative care; primary health care.

INTRODUCTION

Thirty thousand people die from chronic obstructive pulmonary disease (COPD) each year in the UK, almost as many as die from lung cancer, and with health and social care needs that may be at least as great.[1,2] Uncontrolled symptoms, including breathlessness, cough, fatigue, anorexia, anxiety, depression, and pain are widely experienced.[3] At least one-third of patients who die from COPD have had little contact with services in the year before their death.[3] Studies suggesting that advanced COPD patients have palliative care needs have been limited by being unrepresentative, or by being purely qualitative, or by relying on retrospective proxy accounts.[1–5] They have led to increasing calls for the palliative care of patients with advanced COPD.[6–9] Despite growing interest, palliative care needs in COPD have not been described, nor has their prevalence been measured prospectively. There is no reliable guidance for generalists or specialists on how COPD sufferers who may have palliative care needs should be identified or how such needs should be discussed. Added to this has been the uncertainty about prognosis in advanced COPD. There is no evidence to support the making of a prognosis of less than 2 years in individuals with advanced COPD, irrespective of respiratory disease severity.[10–12]

According to the World Health Organization, 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.'*[13]

Palliative care and end-of-life care are terms that are often used interchangeably, but this can generate a confusion that conceals differences in needs and priorities.[14] In designing this study of palliative care needs, the definitions and approaches developed by Higginson *et al* for the conceptualisation of needs have been used.[15] The study has sought to identify patients in the care of UK GPs, who have advanced COPD and palliative care needs, and to define those needs.

METHOD

A cross-sectional interview study was conducted between January and October 2007 in people with advanced COPD, to determine the proportion of patients with palliative care needs and to describe their needs.

Palliative care needs were defined as having: uncontrolled severe symptoms in COPD despite optimal treatment of the disease; information needs about the risk of death, about prognosis, and about the

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How this fits in

Increasing calls for better end-of-life care for patients with advanced chronic obstructive pulmonary disease (COPD) reflect the large numbers of people who die from the disease and their considerable unmet needs. Care of advanced COPD is complex, not least because prognosis is uncertain. This research has assessed the nature and prevalence of palliative care needs in patients with advanced COPD in primary care. Contrary to assumptions that have been made for this group of patients, few report end-of-life care needs, and in most the palliation of breathlessness is their main concern.

availability of treatment to control symptoms; and a need for choice about place and priorities of future treatment in the event of worsening disease.

Subjects

Eligible subjects were patients in the care of GPs, with a diagnosis of COPD and at least two of the following: forced expiratory volume in the first second (FEV$_1$) <40% of predicted;[16] hospital admission for COPD or acute exacerbation of COPD in the previous 12 months; long-term oxygen therapy (LTOT); cor pulmonale; use of oral steroids; and being housebound. Patients with advanced cancer, severe alcohol-related or mental health problems, or learning difficulties were excluded. Subjects had to have an FEV$_1$ of less than 40% predicted according to locally validated prediction equations if their body mass index (BMI) was ≤30 kg/m^2,[17] or an FEV$_1$ less than 30% of expected with a BMI ≥30 kg/m^2, or an FEV$_1$/height^2 ≤0.3.17,[18] The threshold of FEV$_1$ <40% was used because the majority of subjects were over 70 years, and prediction equations for spirometry values in this age group are less reliable.

Setting

The study took place in the London Boroughs of Lambeth and Southwark. Lambeth was the 19th most deprived of 354 boroughs in England and Wales, and Southwark was the 26th.[19] Patients were identified from GPs' COPD and oxygen registers. Practices were recruited by a local GP and accepted secondment of a researcher to identify patients from the medical records, and to send letters to patients on their behalf.

Development of measures

A purpose-designed questionnaire of palliative care needs was devised in a qualitative pilot study with 20 patients.[20] The topic guide for the qualitative interview study was based on a review of the literature including a retrospective survey of 209 patients who died from COPD.[3] Patients were interviewed to identify their most pressing needs for health and social care with respect to symptoms, information, and choice about place of care. The interview data in the earlier qualitative study were analysed using the framework approach to explore, compare, and contrast key themes.[21,22] The final questionnaire reflecting patients' needs was piloted in 10 patients. It is available online. The questionnaire content is summarised in Box 1, included the Medical Research Council (MRC) Dyspnoea Scale, pain questions from the Aberdeen, London and Leeds Pain Survey, the Eastern Co-operative Oncology Group (ECOG) performance status measure, questions on dignity drawing on the work of Chochinov *et al*.[23–25] Questions were mainly closed in style using Likert scales for graded responses, but open questions were used to expand responses or to record new issues. Additional measures included the Hospital Anxiety and Depression Scale (HADS), and the Clinical COPD Questionnaire.[26,27]

Breathlessness has been described as the most important symptom in COPD.[3,4] To identify the most severely affected patients, a composite severe breathlessness variable was developed, amalgamating the five-point ('not at all' to 'every day') breathlessness frequency variable with the severity dimensions of 'breathlessness unrelieved by treatment', 'breathlessness needing more help', and 'breathlessness sitting or talking', from three other breathlessness variables in the questionnaire. Predictors of severe breathlessness were sought in demographic characteristics, other symptoms, impact on daily living, and use of drugs and services.

General and specific prompts were offered to ensure several opportunities were given to discuss information needs in COPD including information about current breathing problems, medicines, the future, symptom control, disease progression, people who might help, who to contact, what would be desired in another acute exacerbation, what to expect, and the desired style of information. Information questions avoided suggesting specific information goals or categories. Subjects were not asked whether they had discussed prognosis specifically or whether a

Box 1. Content of the interview-administered questionnaire[a]

- Symptoms: breathlessness, including Medical Research Council (MRC) Dyspnoea Scale, cough, pain (questions derived from the Aberdeen, London and Leeds Pain Survey), tiredness, loss of appetite, sleeplessness, low mood, anxiety.[21,22]
- Medications
- Comorbidity
- Information (source, range, quality)
- Managing
  - inside home (activities of daily living)
  - outside home (scope of travel, contacts, transport)
- Informal carers
- Eastern Cooperative Oncology Group (ECOG) performance status measure[24]
- Contact with healthcare services
  - primary care
  - hospital and pulmonary rehabilitation
- Acute exacerbations
- Dignity
- Spiritual understanding
- Sociodemographic characteristic

[a] *The qestionnaire can be viewed at: http://tiny.cc/copd*

prognosis had been offered, since there is no evidence that accurate prognosis (less than 2 years) can be made in advanced COPD, and the researchers wanted to avoid suggesting such discussions might be appropriate.[10–12]

Existential issues are important in palliative care at the end of life.[28,29] In COPD patients in Hong Kong who took 'Do not intubate and ventilate' decisions, Pang *et al* categorised patients' existential concerns as the will to live, life value, and concerns about death and dying.[29] Direct reference was not made to the meaning or value of life at interview in this study, but subjects were indirectly given the opportunity to consider existential issues at five points in the interview, including: 'Do you want more information about what the future holds for you?', 'What will happen if you get another attack or episode?', 'Have you made plans about care you might or might not like in the future?', 'Have you discussed plans or thoughts with anyone about future care?', 'Can you tell me a bit more about this?', 'If no or not much, would you like the opportunity of discussing future care with someone?', 'Do you feel you have been able to show how you are feeling with family and friends?', 'With your GP, do you feel able to ask everything you want to?', and 'Is there any treatment that you would not want again?'.

Data collection

Subjects were interviewed in their own homes. Interviews lasted 1.5–3 hours. Informed consent was obtained and confidentiality was assured. Subjects were advised that their GPs would be informed about the results of their lung function tests but no other information would be given to their GPs without their permission. The semi-structured questionnaire was followed by the measurement of height, weight, BMI, and spirometry using the Microlab electronic spirometer (Micromedical Ltd, Chatham, UK). Spirometry was conducted according to the (American Thoracic Society/European Respiratory Society [ATS/ERS] guidelines).[30] Interviews were tape-recorded and the answers to open questions were transcribed. Index of Multiple deprivation (IMD) scores for patients' postcodes were obtained from the UK Government Department for Communities and Local Government.[31]

Analysis

Association was sought between categories of breathlessness and the other categorical variables using the χ^2 test, and between symptom categories and continuous variables (for example, age, lung function) using tests of correlation (Spearman's rho). Optimal treatment was defined from the Global Initiative for Obstructive Lung Disease (GOLD) guidelines.[32]

The use of inhaled long-acting bronchodilators (beta-agonist or anticholinergic) in combination with inhaled steroids was considered to be indicated in a confirmed diagnosis of COPD if the FEV_1 was less than 50% of predicted. The sensitivity and specificity of predictors of severe breathlessness were defined using receiving operator characteristic curves (ROC). ROC curves are the standard tool for assessing the predictive accuracy of a model or test. They plot the sensitivity of a test (rate of true positives) against 1 — specificity (rate of false positives). Answers to open questions were recorded verbatim in the database and hand-searched for evidence of existential concerns, end-of-life care concerns, knowledge or beliefs about prognosis, future care, future plans, and sharing of those plans with professionals, family, or friends.

RESULTS

Forty-four of 55 (80%) practices approached took part (mean list size 7715 patients; standard deviation 3983; range 1679–23 685). Participating practices were larger than non-participating practices, but there were no differences between them in the prevalence of diagnosed COPD (0.97 versus 0.91: $t = 0.86$; $P = 0.48$), or in the points earned for quality of care (0.98 versus 0.91: $t = 2.5$; $P = 0.09$).[28] Two hundred and eighty-nine eligible patients were identified;

Table 1. Characteristics of participating patients with advanced COPD (*n* = 145)

Characteristics	*n* (%), unless otherwise stated
Male	73 (50.3)
Age, years	
Mean, (SD; range)	71.63 (9.7; 32–93)
≤60	23 (15.9)
61–70	32 (22.1)
71–80	67 (46.2)
≥81	23 (15.9)
Marital status	
Married/living with partner	54 (37.2)
Divorced/separated	20 (13.8)
Widowed	48 (33.1)
Single	23 (15.9)
Number in the household	
1	68 (46.9)
2	60 (41.4)
≥3	16 (11)
Ethnicity	
White	134 (92.4)
All black groups	8 (5.6)
Indian	2 (1.4)
Other	1 (0.7)
Employment activity	
Retired	116 (80)
Unable to work (due to illness)	17 (11.7)
In paid work	4 (2.8)
Full-time working at home (looking after dependants)	8 (5.5)
Ever in paid employment or self-employed	135 (93.1)
Last job	
Manager	13 (9)
Foreman/supervisor	11 (7.6)
Employee	97 (66.9)
Self-employed	16 (11)
Not applicable	7 (4.8)
Education	
Education after 16 years	14 (9.7)
University degree or equivalent	9 (6.2)
Smoking	
Ever smoked	140 (97)
Smoker at time of interview	50 (34.5)
Living arrangements	
Own home	30 (20.7)
Rented home	105 (72.4)
Home of relative	2 (1.4)
Other	6 (4.1)
Index of multiple deprivation (IMD)	
Mean (SD; range)[a]	36.7(9.7–59)
Mean IMD for Lambeth and Southwark (SD; range)	34.1(7.1–59)
Cared for now due to illness/disability or old age	
Yes, by person in the household	65 (44.8)
Yes, by person not in the household	43 (29.7)
Lung function	
Mean percentage of predicted FEV_1 (SD; range; 95% CI)	29.1 (9.5; 9–78[b]; 13 to 45)
Mean FEV_1/FVC (SD; Range; 95% CI)	0.4 (0.11; 0.15–0.76[c]; 0.22 to 0.58)

FEV1 = forced expiratory volume in first second. FVC = forced vital capacity. IMD = Index of Multiple Deprivation. SD = standard deviation. [a]National mean IMD in 2007 was 21.6; the higher the IMD the greater the deprivation. [b]Subject with % expected of 78% was aged 93 years, with FEV1 of 0.7 l, FEV1/height2 = 0.33. [c]Five subjects with FEV1/FVC >0.7 had FEV1 less than 0.87 l (4 <0.53 l), and none could sustain forced expiration due to frailty.

24 were ineligible because of inadequate English (*n* = 3), exclusion criteria reported later by the GP (*n* = 7), admission to hospital (*n* = 1), death before contact (*n* = 6), and death before interview (*n* = 7). One hundred and sixty-three (61.5%) of the remaining 265

Table 2. Reported symptoms, quality of life, receipt of care, and performance status (n = 145)

COPD symptoms	*n* (%)
Breathlessness frequency	
On several days or fewer	15 (10.3)
On most days	16 (11.0)
Every day	111 (76.6)
Only with a chest infection	3 (2.1)
Severe breathlessness[a]	63 (43.4)
Cough	
On several days or fewer	36 (24.8)
On most days	17 (11.7)
Every day	74 (51.0)
Only with a chest infection	18 (12.4)
Pain, other than an everyday headache	
On several days or fewer	86 (59.3)
On most days	20 (13.8)
Every day	38 (26.2)
Not sure	1 (0.7)
Loss of appetite	
No	59 (40.7)
Yes	22 (15.2)
Sometimes	26 (17.9)
Appetite is always small	38 (26.2)
Weakness/tiredness/fatigue	
On several days or fewer	58 (40.0)
On most days	20 (13.8)
Every day	67 (46.2)
Difficulty sleeping at night	
On several days or fewer	80 (55.2)
On most days	16 (11.0)
Every day	49 (33.8)
Low mood	
On several days or fewer	108 (74.5)
On most days	15 (10.3)
Every day	22 (15.2)
Anxiety or panic	
On several days or fewer	128 (88.2)
On most days	8 (5.5)
Every day	9 (6.2)

[a] *Breathlessness every day and one of 'breathlessness unrelieved by treatment', 'breathlessness needing more help', 'breathlessness sitting or talking'.*

agreed to an interview. There were no differences between participating and non-participating patients in age, sex, deprivation score (IMD), spirometry, or use of oral steroids. Participating patients were more likely to have been prescribed long-term oxygen therapy (67/163 versus 32/126; $\chi^2 = 7.785$, $P = 0.005$), and were more likely to have been admitted to hospital for COPD (81/163 versus 48/126; $\chi^2 = 3.868$, $P = 0.049$).

One hundred and forty-five of the 163 patients interviewed met the inclusion criteria. Their characteristics are shown in Table 1. Most were in lower socioeconomic groups, most had low educational attainment, almost half lived alone, and one-fifth owned their own homes.

Reported symptoms and impact on daily living are shown in Tables 2 and 3. One-hundred and thirty-four (92%) subjects described breathlessness as the problem causing the most difficulty. All 58 (40%) subjects who reported pain other than a headache every day or most days were on prescribed analgesics. Of these, 26 had pains that they were unable to list in broad anatomical categories (for example, head, abdomen, or limb). There was a strong association between the ECOG score and reported breathlessness frequency ($\chi^2 = 60.4$; degrees of freedom [df] = 9; $P<0.001$) and severity ($\chi^2 = 14.5$; df = 3; $P = 0.002$). Eighty of 82 subjects with severe breathlessness described themselves as capable of limited self-care or as completely disabled (according to ECOG).

Comorbidity

Comorbidities were reported by 106 patients (73%). The most common were ischaemic heart disease (59, 41%), arthritis (33, 23%), mental illness (16, 11%), diabetes mellitus (11, 8%), and stroke (9, 6%). There was no association between the number of comorbidities and the degree of severity of breathlessness or of impairment of lung function.

Predictors of severe breathlessness

Predictors of breathlessness were sought using the composite severe breathlessness variable. Eighty-two (57%) subjects had severe breathlessness as defined by this composite severe breathlessness variable. There were significant correlations and associations between many combinations of variables and severe breathlessness, but no combination was sufficiently specific to be useful as a predictor of severe breathlessness in a clinical setting. Among the 63 patients in the study aged 75 years and younger, reporting of grade 5 breathlessness in the MRC Dyspnoea Scale had a specificity of 93.5% (very few false positives) and a sensitivity of 52.7% (almost 50% false negatives) in predicting severe breathlessness (by the composite variable).

Drug use, use of services, and choice about place of care

Reported drug use is shown in Table 4. Thirty per cent of subjects were on suboptimal treatment as defined in the GOLD guidelines. There was no association between reported drug use and symptoms, impact on daily living, respiratory-specific quality of life, rate of exacerbations, or use of services. The 67 (46%) subjects who reported having attended pulmonary rehabilitation were more likely to have been

Table 3. Reported symptoms, quality of life, receipt of care, and performance status (*n* = 145)

COPD symptoms	***n* (%)**
MRC Dyspnoea Scale	
1–3: Breathlessness at worst resulting in slower walking than contemporaries	12 (8.3)
4: Stops for breath after walking 100m	74 (51.0)
5: Too breathless to leave the house, or breathless dressing and undressing	59 (40.7)
Hospital Anxiety and Depression Scale (HADS)	
High risk of anxiety: HAD-A ≥8[b]	51 (35.2)
High risk of depression: HAD-D ≥8[c]	63 (43.4)
Chronic COPD Questionnaire (CCQ)	
Overall mean score (SD; range)[d]	3.0 (1.1; 0.1–5.7)
Mobility	
Able to get out of home	66(45.5)
Can get out with the help of portable oxygen	15 (10.3)
Difficulty with activities	
Getting washed or bathing	110 (75.8)
Getting dressed	87 (60.0)
Doing the housework	131 (90.3)
Preparing meals	93 (64.1)
Getting around the home	73 (50.3)
Looked after or receiving special help	113 (77.9)
By person in own household	65 (44.8)
By person in another household	49 (33.7)
Eastern Cooperative Oncology Group (ECOG) performance status	
Restricted but ambulatory with light work	3 (2.1)
Ambulatory and capable of all self-care	12 (8.3)
Capable of limited self-care	85 (58.6)
Completely disabled	45 (31.1)

MRC = Medical Research Council. [a]Breathlessness every day and one of 'breathlessness unrelieved by treatment', 'breathlessness needing more help', 'breathlessness sitting or talking'. [b]In a general practice population HAD-A had a prevalence of 18.5% (95% CI = 16.5 to 20.6%) (ref). [c]In a general practice population HAD-D had a prevalence of 28.8% (95% CI = 26.3 to1.5%) (ref). [d]Mean score of 3.0 across three domains of symptoms, functional state, and mental state equates to mean frequency of "several times" in the six questions using frequency, and mean severity of 'moderately limited' in the four domains using severity.[29]

on optimal treatment (odds ratio [OR] 4.5; 95% confidence interval [CI] = 1.6 to 12.3), more likely to have received oral steroids (OR 6; 95% CI = 1.8 to 19.7), and more likely to have had a nurse involved in their COPD care (OR 3.4; 95% CI = 1.5 to 7.4).

Forty-four (30%) subjects reported regular contact with their GP 3-monthly or more often, with 97 (67%) attending when needed. Eighty-seven (60%) had regular contact with hospital. Attendance at the GP or at hospital was not associated with the degree of severity of breathlessness or of functional impairment.

One hundred and three (71%) reported acute severe exacerbations within the previous 2 years, of whom 102 were admitted to hospital. Ninety-five (93%) thought hospital admission was the right action, and one thought it was not right. If very unwell again, 86 (84%). would have wanted to go back to hospital, but 13 (13%) would not have wanted to go back because of dislike of the physical environment or the food, because of worry about infections such as meticillin-resistant *Staphylococcus aureus* (MRSA), or because they felt they could be equally well treated at home. None felt admission was futile, none expressed existential concerns about admission, and none wanted to risk treatment at home rather than face admission.

Information needs

Ninety-three (64%) subjects reported that they had enough information about their current breathing problems, 102 (70%) had been able to ask everything they wanted to about their chest trouble, and 99 (68%) had been given the information in a way that was easy to understand. More information was wanted about how to control breathlessness by 78 (54%), about what to expect with their chest trouble by 61 (42%), about their medication by 84 (58%), and about the future by 54 (37%).

Plans for future care and existential needs

Future care was reported to have been considered by 31 (21%) subjects, and 44 (30%) made specific mention of plans that had been discussed. Twenty-seven (19%) reported never having considered their future with COPD. Fifty-one (35%) had given consideration to their future with COPD, including eight who planned to seek help from carers, eight who expected support by their families, 10 who planned to move house or move into a care or nursing home, four who had planned their funeral arrangements, two who had been referred to palliative care, two who had written a will, one who had received a 'do not resuscitate' order, and 15 who had made other individual comments. Explicit statements about preparation for death were not made but some patients were clearly approaching that position, as the following verbatim comment by a 65-year-old married man with very severe breathlessness indicates:

'*I have been told by the hospital that I have a short life expectancy and I was referred to end-of-life care. This made me a bit frightened, and made me think of death a lot. I try and shove it to the back of my mind. I feel like giving back nippy!*' [nippy is the popular term for non-invasive positive pressure ventilation — NIPPV]

Existential concerns, that is to say concerns about the meaning or value of life in relation to dying or possible death, were not expressed in the need for information about the future, in plans considered for the

Table 4. Reported use of respiratory drugs in patients with advanced COPD (*n* = 145)

Drug	*n* (%)
Inhaled short acting beta-agonists	137 (94)
Inhaled LABA supplied in separate inhaler	18 (13)
Inhaled steroids supplied in separate inhaler	29 (20)
Inhaled tiotropium	91 (63)
Inhaled combined steroids and LABA	88 (61)
Inhaled LABA and tiotropium	61 (42)
Oral corticosteroids (including six held in reserve)	32 (22)
Theophyllines	9 (6)
Not on inhaled long-acting bronchodilators and inhaled steroids[a]	43 (30)
Oxygen	59 (41)
Cylinder supply without concentrator	14 (10)
Concentrator	45 (31)

LABA = long-acting beta agonists. [a]Long-acting bronchodilators means LABA or tiotropium.

future, in the reporting of action preferred in the event of a future exacerbation, or alongside open statements about the expectation of death from the disease, the making of wills, and anticipated dependence on relatives and carers.

DISCUSSION

Summary

In patients with advanced COPD recruited in primary care, palliative care needs were identified in the need for control of symptoms, principally breathlessness. Existential need was not reported and few talked about care needs in terms of 'end-of-life care', even among those who were aware of the likelihood of death from the disease and who had plans that included funeral arrangements or palliative care. It is possible that the most vulnerable patients for whom life with COPD had become unbearable did not participate. Despite the severity of their disease, 30% of the participants were on suboptimal treatment and more than half had never been referred to pulmonary rehabilitation. Thirty per cent of these advanced COPD sufferers had not been admitted to hospital in the previous 2 years. From these findings it is evident that not all of the most severely affected people with COPD were receiving active treatment.

Strengths and limitations

A high response rate (80%) was obtained among the general practices invited to take part. The response rate among patients (61%) was less satisfactory, but the finding that responders were at least as severely affected as non-responders and were no different in demographic characteristics and deprivation, was reassuring. More than 98% of the UK population is registered with a GP, so it is unlikely that many subjects will have been excluded by recruiting from the lists of GPs. It is likely that some subjects with severe disease will have been missed due to underdiagnosis of COPD.[34]

The study included five frail older subjects with FEV_1/forced vital capacity (FVC) ratios that did not meet entry criteria because of their inability to sustain forced expiration due to breathlessness and frailty. Predicted values for subjects aged over 75 years are unreliable.[17] Anxiety or panic and depression were reported at almost twice the rate observed in general practice populations.[35]

Almost all of the subjects were white, despite being recruited in areas in which 26% of the population was black. The ethnicity of the subjects was similar to the ethnicity reported in a retrospective survey of COPD deaths in the same area 6 years previously.[3] People in black ethnic groups are at least as likely to smoke as those in the population as a whole, although men in the UK born in the Caribbean have a low standardised mortality ratio of 0.7 for lower respiratory disease.[36] The low representation of people of black ethnicity may reflect a combination of higher rates of underdiagnosis, a lower response, and a disproportionately low prevalence of severe COPD among older black people in south London. Across the whole sample, it is unlikely that many more severely affected people with diagnosed COPD were excluded or excluded themselves, since responders were at least as severely affected as non-responders.

Some subjects in this study who had end-of-life care concerns may not have been identified, either through a desire not to

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Ethical approval

Ethical approval was obtained from the Research Ethics Committee (REC) of King's College Hospital NHS Foundation Trust (05/Q0703/91).

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests. All of the authors are independent of the funders.

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Discuss this article

Contribute and read comments about this article on the Discussion Forum: **http://www.rcgp.org.uk/bjgp-discuss** embarrass the researcher, or through a reticence to acknowledge their concerns. Limited declaration of end-of-life care concerns may also have resulted from the interview strategy, which was careful to avoid suggesting that patients were approaching the end of life, although end-of-life concerns were addressed. Against this there is good evidence that end-of-life concerns were not overlooked. Almost all who had been admitted to hospital said they would want to be readmitted in the event of a further severe exacerbation. Subjects reported a wide range of symptoms, and 40% described themselves as profoundly incapacitated. Reports were in keeping with the level of lung function observed, and there was no reason to suspect that subjects were inhibited in reporting negative perceptions.

Comparison with existing literature

The findings of this study contest expectations that many people with advanced COPD in primary care settings wish to discuss care needs in terms of 'end-of-life care'.[3,6–9,37] The experience of palliative care specialists suggests that there are individuals with advanced COPD who have end-of-life care needs that are comparable to the needs of people with advanced cancer. In this study, people with advanced COPD in primary care seldom wished to frame their needs within an 'end-of-life care' context. This presents a challenge to the conceptualisation of the palliative care of chronic non-malignant disease within an end-of-life care strategy such as that promoted by the UK Department of Health.[38]

Palliative care needs in advanced COPD were formulated more in terms of the palliation of symptoms than in terms of the need for end-of-life care or advance care planning. For those with optimised COPD treatment, other routes for the treatment of their breathlessness need to be investigated.[39] The best predictor of severe breathlessness in this group of subjects is category 5 in the MRC Dyspnoea Scale in patients aged 75 years and under. Routine use of the MRC Dyspnoea Scale is currently the subject of incentive payments in UK general practice.[33] The identification of severe breathlessness is less reliable in individuals over the age of 75 years.

Most, if not all, of these patients were living with COPD rather than dying from it. Perhaps those for whom life or the participation in research seemed pointless or unbearable were among the 38% of patients who did not take part. Such patients cannot be identified easily through practice-based registers but their prevalence demands definition nonetheless.

Implications for practice

Limited reporting of end-of-life care needs in these subjects with advanced COPD recruited in primary care questions the current direction of palliative care service development for chronic non-malignant disease. Patients whose symptoms in advanced disease have increased slowly over years rather than weeks may experience continuing 'response shift' in their experience of their disease, and as a result may focus on the struggle to live rather than on end-of-life care.[40] There is a striking contrast between these patients and those with severe breathlessness from advanced malignancy in whom breathlessness is usually associated with impending death in days or weeks.[39,41] Severe breathlessness in advanced COPD is a daily reality. Many, if not most, of these patients know they may die from the disease, but death is not imminent in most, and is not specifically signalled by their breathlessness. In this context, the palliation of breathlessness in advanced COPD appears more important for patients than consideration of end-of-life care.

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