

Palliative care needs in COPD - what evidence and what direction should we take?



Patrick White
King's College London
Department of General Practice
and Primary Care



What evidence?

What direction?

- Why do we think people with COPD have palliative care needs?
- What palliative care needs might they have?
- Can we identify COPD patients with palliative care needs?



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Mortality and end of life care

- 24000 deaths in England / Wales 2004 compared to 28000 from lung cancer
- Mortality in severe COPD between 36% and 50% at 2 years

Connors et al. Am J Respir Crit Care Med 1996;154(4):959-67

Almagro et al. Chest 2002;121(5):1441-8.

Why do we think people with COPD have palliative care needs?

- Heavy burden of symptoms
- Symptoms are more severe than lung cancer but services are limited with virtually no end of life care

Gore et al Thorax 2000;55(12):1000-6.

Edmonds et al 2001 Palliat Med 2001;15(4):287-95.

Elkington, White, et al Palliat Med 2005;19 485-91

How are people who die from COPD affected?

In the last year of life

40% had breathlessness unrelieved

68% had low mood unrelieved

51% had pain unrelieved


20% did not know they might die

70% died in hospital (for 25% of whom it was not the best place to die)



Service Provision

- One third of patients lacked regular follow up in hospital or in the community
- One third of patients saw their GP less than 3 monthly or never
- Lack of home-based services although many patients were housebound



Why is the palliative care of COPD an issue?

- Almost as many people die from COPD as die from lung cancer
- Care of COPD in severe disease is less than the care of lung cancer
- People who die from COPD have a high chance of being isolated, receiving minimal care, being poorly informed and having symptoms untreated



The background to palliative care of COPD

- Growing drive for providing palliative care for patients with advanced COPD
- Repeated assertions that COPD patients with <1 yr prognosis can be identified
- Assumption that because patients die from chronic illness their deaths can be prepared



Death Mask of Sir Thomas Lawrence 1830,
National Portrait Gallery, London, unknown artist



Palliative care of COPD as a non-malignant disease?



- End of life care strategy of NHS
- Crescendo of calls for recognition of palliative care needs of advanced COPD

Seamark J Roy Coll Phys 2007;
Rocker J Pall Med 2007; Curtis et al Eur Resp J 2007

- UK Gold Standards Framework suggests that using available cross-sectional parameters we can identify people with COPD who are within a year of death

<http://www.goldstandardsframework.nhs.uk>



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What should we be thinking about?

- Symptom control
 - Breathlessness, depression, anxiety, pain,
- Information needs
 - What works, prognosis, best place to be treated
- Preferred place of care
 - In the event of another exacerbation....?



South London audit of COPD palliative care referrals

81 referrals over 2 years

68 deaths

14 discharges (2 re-referred)

1 still under palliative care

Hall, Edmonds, Beynon, and White. 2006
Audit of palliative care of COPD. St Christopher's
Hospice.

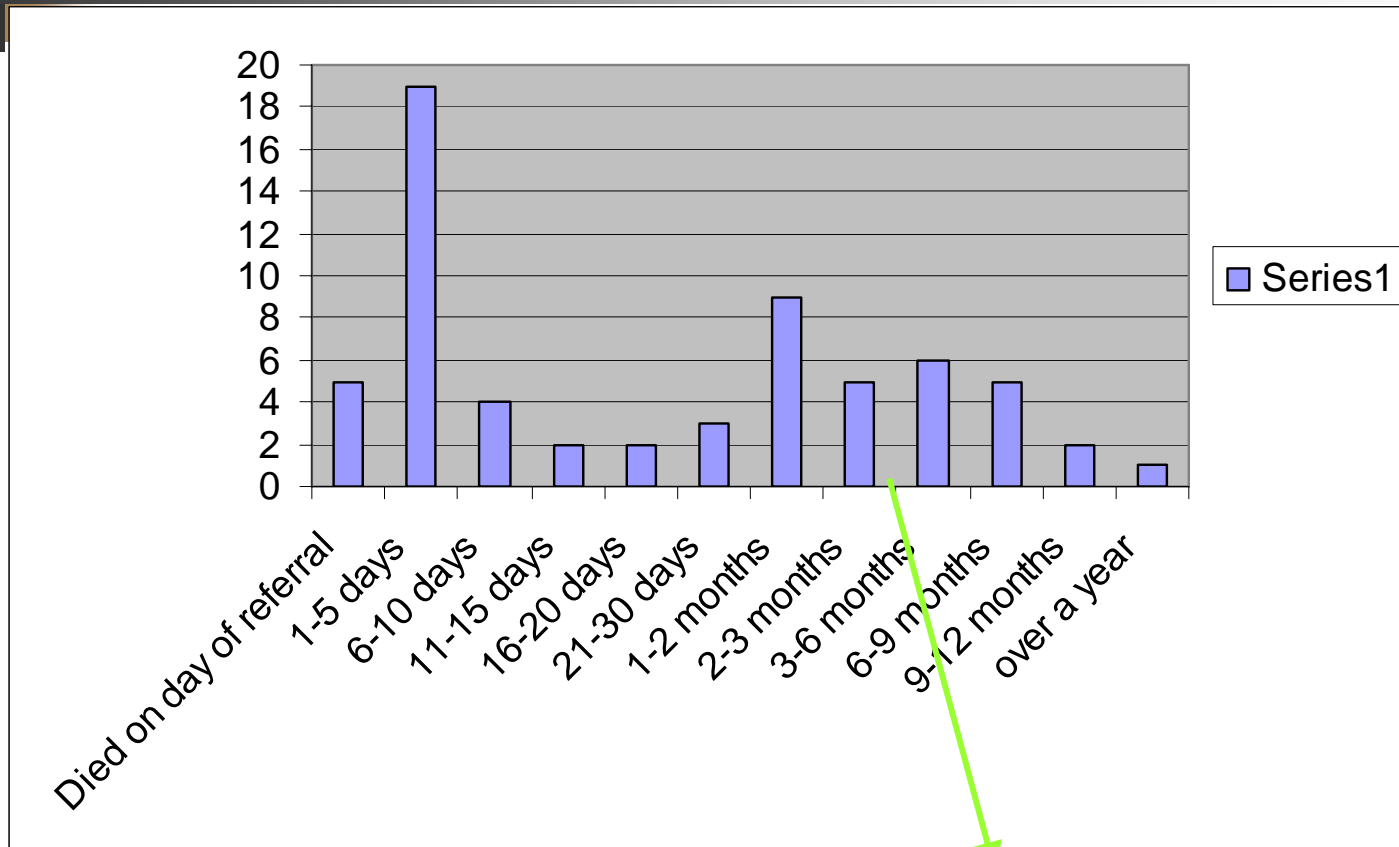


South London audit of COPD palliative care referrals

- mean age at first referral = 74.4 years
 - range = 50 to 92 years.
- Mean age at death 74.8 yrs (50-92)

Hall, Edmonds, Beynon, and White. 2006

Time between first referral to palliative care team and death



55 out of 63 dead at 6 months



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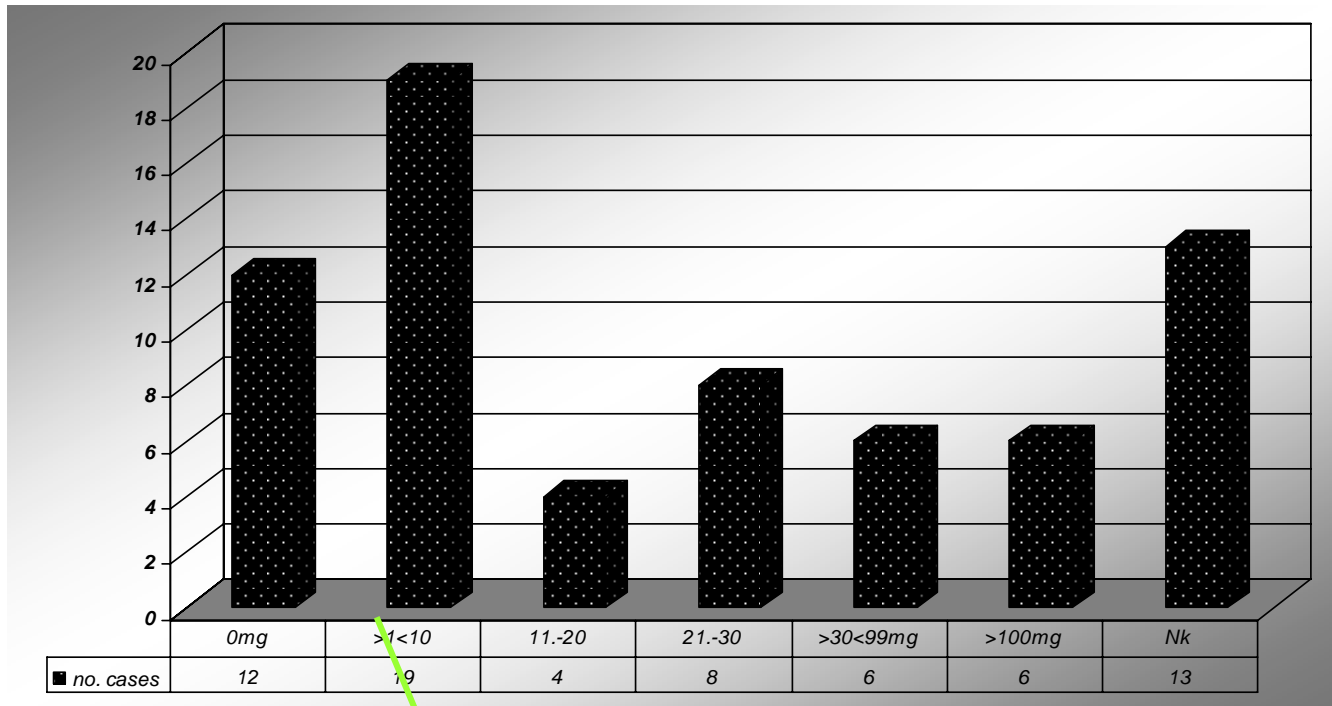
81 referrals over two years from > 300 practices

1 referral from 7+ practices per year

1 referral per average practice over seven years

Referrals would have to increase x 7 to make one / practice / year

EDDM last 6 wks life (EDDM=equivalent daily dose morphine)



56 out of 68 received opiates

Hall, Edmonds, Beynon, and White. 2006



How big is the problem in primary care?

- How many patients with COPD are we likely to have with palliative care needs?
- What needs are they likely to have?
- What can we do about their needs?

Prospective study of palliative care needs of advanced COPD



Prospective study of palliative care needs of advanced COPD

White, White, Edmonds, Moxham, Gysels, Shipman.

Funded by Guy's and St Thomas Charity

- No prospective surveys of palliative care needs in COPD
- No reliable guidance for generalists or specialists on palliative care needs in COPD
- Our aim was to identify patients with palliative care needs and to define their needs

Palliative care needs in COPD

- Community based survey
- Patients with severe COPD from GP registers
- Interview questionnaire
- Lung function, BMI, HADS, Respiratory specific quality of life, MRC dyspnoea scale, Pain questionnaire

Patients in the study

- 44 (80%) of 55 practices took part
- Data on 145 (61%) with advanced disease
 - Mean age 72 years (46-93), Female 50%
 - FEV1 <40% expected (Quanjer et al)
 - 88% short of breath most days/everyday
 - 45% housebound
 - 75% had a carer (45% in the home)
- **Respondents at least as severe as non-respondents**

What were the priorities of these people with advanced COPD?

- Severe breathlessness 57%
- Breathlessness every day and one of
{breathlessness unrelieved / breathlessness
washing or dressing / breathlessness talking}
- MRC dyspnoea scale category 5 31%
- Too breathless to leave the house, or SOB when
dressing or undressing
- Breathlessness the most important problem 92%

Summary Conclusions

- Most of these patients with advanced COPD had been admitted with an exacerbation
- Most felt admission was the right action
- Most would want admission again if they became unwell to the same extent
- None expressed existential concerns relating to their stage in life despite severe breathlessness and impairment

Summary Conclusions

- We were unable to identify patients with advanced COPD who reported that hospital admission would be the wrong response to an acute severe exacerbation
- The place of a traditional end of life care approach in a primary care setting in response to an acute exacerbation of COPD in those with severe disease is likely to be limited to a few patients



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Making a prognosis in COPD

- Mortality in severe COPD is between 36% and 50% at 2 years

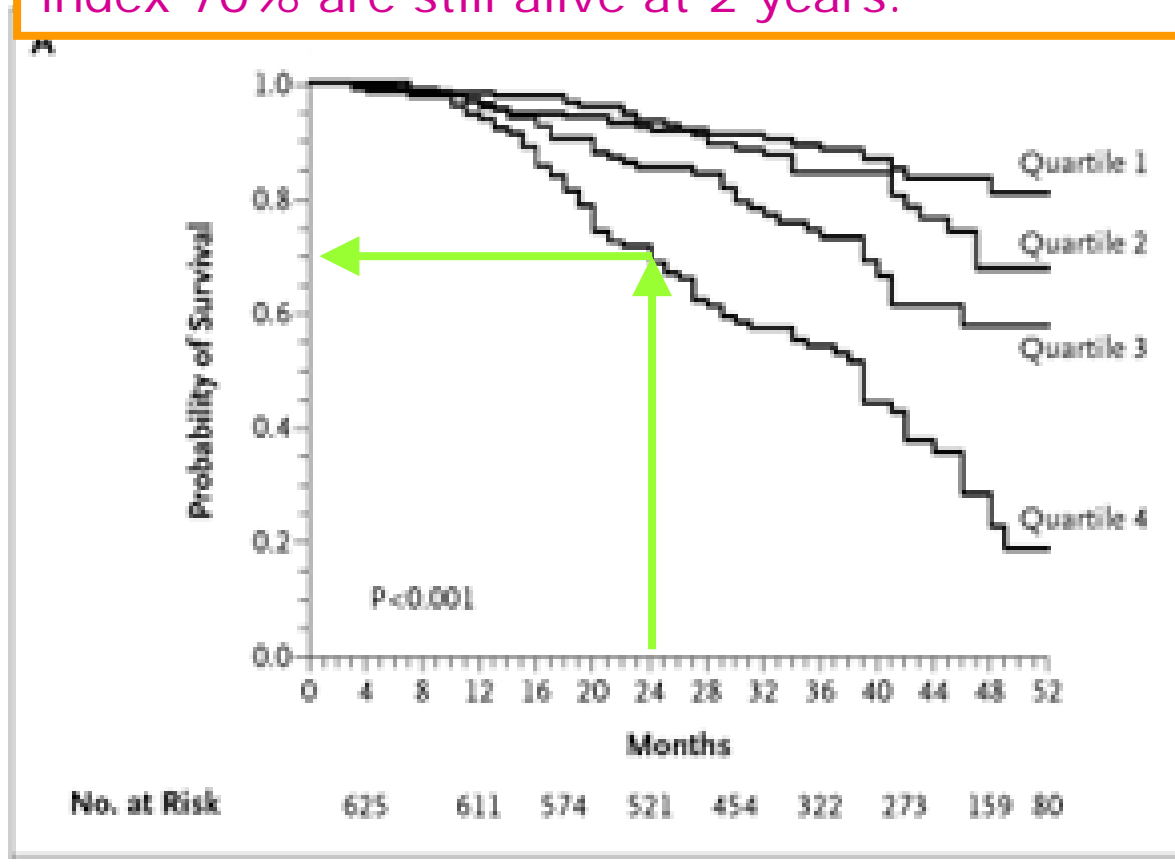
Connors et al. *Am J Respir Crit Care Med* 1996;154(4 Pt 1):959-67

Almagro et al. *Chest* 2002;121(5):1441-8

- Predictors of mortality include
 - Low BMI, Low FEV1, dyspnoea, low 6MWD, Fat free body mass, number of hospital admissions, maintenance oral steroids, quadriceps strength, congestive heart failure, low albumin, cor pulmonale, oxygen saturation,

The BODE index

Even in the most severe category of the Bode index 70% are still alive at 2 years.



Score
Range 0-10

| | |
|----|------|
| Q1 | 0-2 |
| Q2 | 3-4 |
| Q3 | 5-6 |
| Q4 | 7-10 |

Kaplan-Meier survival curve for COPD categorised by BODE Index. Celli et al, NEJM 2004

What evidence is there for a palliative care approach in COPD?

- Needs in advanced COPD are considerable and match those of people with cancer
- Patients with advanced COPD are likely to have arrived at that point gradually
- Prognosis in COPD is not accurate enough to be useful in the short term (<one year)
- There are no useful disease specific indicators which indicate COPD patients suitable for a palliative care register

Summary Conclusions



The place of a traditional palliative care approach (end of life care) in a primary care setting in response to an acute exacerbation of COPD in those with severe disease is likely to be limited to a few patients

Breathlessness is the main concern in advanced COPD

Palliative care of advanced COPD may be best delivered as palliation of breathlessness and other symptoms, with end of life care an issue for a very small minority