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Journal club

Palliative care in severe COPD: how and when?

Palliative care in chronic obstructive pulmonary disease (COPD) is an area that needs development. Existing palliative care models for cancer and chronic diseases such as heart failure do not seem to fit well with problems encountered by patients with COPD. This study obtained qualitative data about living and dying with COPD from serial interviews with 21 patients with end-stage COPD, and their informal and professional carers. The data were coded, themes drawn out and the 'story' of their COPD delineated.

The near-universal pattern was an illness with no clear start, reflecting the insidious onset. COPD became 'a way of life' in the middle, ruled by unpredictable exacerbations and no clear trajectory of illness progression. Patients were symptomatic but described themselves as 'well' between exacerbations, adapting to their breathlessness and accepting it as a natural part of ageing. At the end of the story, death was unpredictable, and patients' expectations of dying were similar to that of people with no chronic illness. Professional carers' narratives often reflected those of their patients, with particular difficulty establishing a likely prognosis and appropriate point of transition to palliative care, influenced by longstanding relationships and established patterns of consultations which were hard to change.

Overall, this study demonstrated that disease progression in COPD can be described as a 'chaos narrative' unlike that of other life-limiting illnesses which have a better defined trajectory. The authors proposed a system of integrated palliative and supportive care assessments throughout the patient journey, prompted by milestones such as hospital admission and starting long-term oxygen therapy, with specialist input for the management of intractable symptoms.

► **Pinnock H**, Kendall M, Murray SA, *et al*. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ* 2011;**342**:d142. doi:10.1136/bmj.d142.

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