

Editorial

Palliative care in people with chronic obstructive pulmonary disease

Andrew Thorns, consultant in palliative medicine, Declan Cawley, research fellow in palliative medicine

[+ Author Affiliations](#)

andrew_thorns@pilgrimshospice.org

Passive acceptance of the illness has implications for end of life care and delivery of services

The fact that chronic obstructive pulmonary disease (COPD) is a terminal illness comes as no surprise to clinicians on acute medical wards, especially as the winter takes hold. Why then are patients surprised when end of life issues are raised or referrals made to hospice services? In the linked study (doi: [10.1136/bmj.d142](https://doi.org/10.1136/bmj.d142)), Pinnock and colleagues postulate that patients passively accept their lot and see the increasing disability as part of normal ageing.¹ The researchers found that, unlike patients with other diseases (such as cancer and heart failure)—who can tell the story of how the illness occurred, events that have unfolded, and their current disease status²—patients with COPD seem to lack this narrative story. The realisation of illness, or “biographical disruption” to their life, is not a conscious thought for these patients. There is no clear point of diagnosis, especially one with a poor prognosis³.



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This lack of biographical disruption stops patients from identifying COPD as a serious illness. Current strategies aimed at identifying patients in their last six to 12 months of life may fail because of this lack of a clear start to the illness as well as the difficulties of making an accurate prognosis.

The delivery of palliative care has moved from end of life care centred on people with cancer to a more proactive and earlier intervention that includes people with diseases other than cancer. Current initiatives on services for patients with chronic lung disease have called for better assessment of patients' and carers' needs and involvement of palliative care services.^{3 4} An accurate holistic assessment of need can guide the delivery of care more effectively than projected longevity, so that those with the greatest need receive the specialist palliative care that they require. This would bypass the problem that clinicians face of knowing when to move to a palliative approach.⁵

Pinnock's concept of passive acceptance of the increasing dyspnoea and disability can be considered either as a weary resignation or a more helpful, comfortable adaptation by patients. The challenge for clinicians when seeing a gradual decline over many years is not to accept this as part of smoking related, accelerated ageing. Instead, they should consider when, or if, the patient is approaching the end of their life and how their care should be adapted. Awareness of this passive acceptance will help professionals to tailor care accordingly.

Transition points are opportunities to prompt professionals to open up discussions about the nature of COPD and the outlook for the future. The authors suggest potential examples, such as the point of diagnosis, the time of retirement for medical reasons, the point at which domiciliary oxygen is needed, or during hospital admissions. For these transition points to be effective clinicians should communicate and explain the current clinical situation and the management approaches. This will require courage to change the current mindset of health professionals in particular and embrace some of the difficult conversations needed with life limiting illnesses.

Neither an acute care approach nor a palliative care approach can meet all the needs of this group of patients. A gradual integration of services allows time to adjust.⁶ Evidence from patients with cancer suggests that early involvement of palliative care is better for patients' quality of life and has no adverse impact on mortality.⁷ Similar research in people with COPD would be helpful.

The challenge will be to integrate a model that traverses acute and palliative care settings, is sensitive to the requirement for active hospital care, deals with the life limiting nature of the condition, and does not overwhelm the limited specialist palliative care services currently available. For example, how should clinicians recognise when a palliative approach is more appropriate than an acute medical one? And, if this is the case, whether they, and the other services involved, have the skills to manage an acutely breathless patient at home when the patient does not want to be admitted to hospital? This is where experience from palliative care services could be most useful.

Several research questions remain. How will patients perceive coming from a mindset of passive acceptance of their medical problem to accepting that they have a life limiting illness? What will be their response to discussions about end of life care with an uncertain prognosis? How and when should clinicians tackle such discussions and manage their own emotions, especially if they have been treating the patient for several years? Questions around service provision and symptom control, especially of dyspnoea, remain. How can traditional palliative interventions developed mainly for cancer be applied to COPD?

Notes

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