

Letter to the Editor

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The conceptual framework for providing palliative care for people with chronic obstructive pulmonary disease (COPD) is a timely step forward and the authors are to be commended for this contribution (Philip et al., 2017). The impact of the inexorable decline experienced by people with advanced COPD is reflected strongly in the framework.

The framework could be further strengthened by using contemporaneous data that reflect the lived experience of caregivers of people with chronic respiratory diseases (Currow et al., 2011). Through undertaking population-based surveys, caregivers of people who have died from end-stage respiratory disease outline the longer duration of the care they provided (when compared with other people with end-stage organ failure) and their perceived unmet needs in help with physical care, information about the disease, and emotional and spiritual support (Johnson et al., 2012). To maintain care over such long periods is one of the greatest demands that anyone can experience and ensuring that people are able to be supported in the role is a crucial part of providing good care. People with advanced respiratory disease were also half as likely to access specialist palliative care services (Johnson et al., 2012) and, given that needs are similar for people late in life whatever the underlying life-limiting illness, this fails to reflect the support that caregivers require (Luddington et al., 2001).

People providing informal care for those with COPD share the burden experienced by many caring for those with chronic progressive illnesses (Gysels et al., 2009). However, they also have concerns directly related to the COPD. Important qualitative studies outline the enormity of the challenges that are faced by caregivers in this setting, especially with fears of breathlessness and acute exacerbations (Farquhar et al., 2017; Gysels et al., 2009). The more breathlessness the person, the greater the burden on caregivers. A meticulous program of work led by Farquhar et al. 2017 (Cambridge Institute, 2016) confirms and expands this understanding, with six caregiver-identified key areas for support and education: (1) understanding breathlessness; (2) managing anxiety, panic, and breathlessness; (3) managing infections; (4) keeping active; (5) living positively; and (6) knowing what to expect in the future. The paucity of information shared with people about their future has been previously noted (Gysels et al., 2009); however, despite these needs, caregivers' education is rarely given systematically and, if they have any at all, it is mostly as a "by-product" of patient clinic attendance (Ewing et al., 2017). A routine approach that addresses these concerns, ideally jointly with the patient, should increase caregiver confidence, improve self-efficacy, and potentially reduce emergency hospital attendance, which mostly occur during "out-of-office" hours when responsibility lies heavily with family members (Hutchinson et al., 2017).

The framework proposed by Philip et al. (2017) would ideally look at the support that caregivers need given the very long periods for which patients will have symptomatic disease requiring support.

References

- Cambridge Institute of Public Health (2016) Improving care and support in advanced COPD: The living with Breathlessness study. Available from <http://www.iph.cam.ac.uk/public-health-policy/policy-themes/endoflife-care/copd/>.
- Currow DC, Farquhar M, Ward A, et al. (2011) Caregivers' perceived adequacy of support in end-stage lung disease: Results of a population survey. *BMC Pulmonary Medicine* **11**, 55.
- Ewing G, Penfold C, Benson JA, et al. (2017) Clinicians' views of educational interventions for carers of patients with breathlessness due to advanced disease: Findings from an online survey. *Journal of Pain and Symptom Management* **53**(2), 265–271.
- Farquhar M, Penfold C, Benson J, et al. (2017) Six key topics informal carers of patients with breathlessness in advanced disease want to learn about and why: MRC phase I study to inform an educational intervention. *PLoS One* **12**(5), e0177081.
- Gysels MH and Higginson IJ (2009) Caring for a person in advanced illness and suffering from breathlessness at home: Threats and resources. *Palliative & Supportive Care* **7**(2), 153–162.

- Hutchinson A, Pickering A, Williams P, et al.** (2017) Breathlessness and presentation to the emergency department: A survey and clinical record review. *BMC Pulmonary Medicine* **17**(1), 53.
- Johnson M, Bowden J, Abernethy AP, et al.** (2012) To what causes do people attribute their chronic breathlessness? A population survey. *Journal of Palliative Medicine* **15**(7), 744–750.
- Luddington L, Cox S, Higginson I, et al.** (2001) The need for palliative care for patients with non-cancer diseases: A review of the evidence. *International Journal of Palliative Nursing* **7**(5), 221–226.
- Philip J, Crawford G, Brand C, et al.** (2017) A conceptual model: Redesigning how we provide palliative care for patients with chronic obstructive pulmonary disease. *Palliative & Supportive Care* **31**, 1–9.