The experience of patients with COPD who access specialist palliative care: a qualitative study

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Background

Patients with end-stage chronic obstructive pulmonary disease (COPD) experience health-related quality of life comparable to, or worse than that of people with advanced non-small cell lung cancer. Access to specialist palliative care is poor for those with COPD, and comparisons with lung cancer patients demonstrate inequalities. National COPD guidelines state that patients ‘should have access to the full range of services offered by multidisciplinary palliative care teams’. Services are being developed to address this inequality, but it is not known whether current models of specialist palliative care are appropriate to the needs of COPD patients.

Aim

To understand the experience of patients with COPD who access specialist palliative care.

Methods

Eight patients accessing any service for one month (outpatient) or one week (inpatient) undertook semistructured interviews (mean duration 34 min). Recordings were transcribed verbatim and analysed using hermeneutic phenomenology.

Results

Perceived benefits of specialist palliative care included reduced frequency of hospital admission, improved physical symptoms, reduced social isolation and a broadened physical environment in which participants could function. Improvements in psychological wellbeing (including improved mood, confidence and self-worth) were also described. Patients were aware of their poor prognosis, but some were initially distressed at the prospect of palliative care referral, mainly due to prior associations between palliative care and death. Perceptions changed following engagement with services, with fear of discharge becoming problematic.

Conclusions

There is much within existing services that works well for people with COPD, but some features of care could be modified, such as patterns of service provision and discharge policy. In contrast with previous literature, participants were aware of their poor prognosis. However, work is needed to dispel negative perceptions of specialist palliative care among COPD patients, as they may form a barrier to access.
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BMJ Support Palliat Care 2012 2: A12
doi: 10.1136/bmjspcare-2012-000196.34

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