Perceptions and Experiences of Patients and Informal Caregivers in Advanced Chronic Obstructive Pulmonary Disease: An Exploratory Study

Fusi-Schmidhauser Tanja[1], Froggatt Katherine[2], Preston Nancy[2]

[1] Palliative and Supportive Care Clinic, Institute of Oncology of Southern Switzerland and Ente Ospedaliero Cantonale, Switzerland
[2] International Observatory on End of Life Care, Lancaster University, United Kingdom

Background

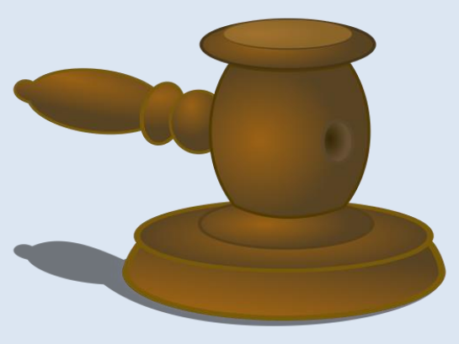
Chronic obstructive pulmonary disease (COPD) is recognized as being a life-limiting condition with palliative care needs. However palliative care provision is seldom implemented in this population. The disease unpredictability, misconceptions about palliative care being only for people with cancer, and only being relevant in the last days of life, often prevents a timely integrated care plan.

Aims and methods

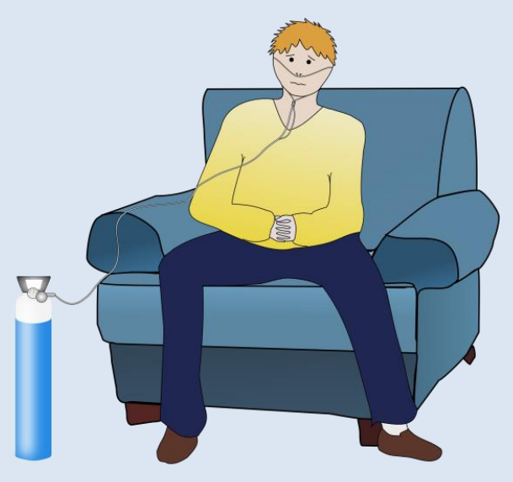
To explore patients and informal carers' experiences about living with COPD and to understand perceptions about palliative care approaches in COPD.

- An explorative descriptive study
- 10 semi-structured interviews with adult advanced COPD patients (GOLD stages 3 and 4) (n=5) and informal carers (n=5)
- Data analysis using thematic analysis

Results



Patients reported a feeling of personal guilt over smoking and towards loved ones and carers blamed patients over a "self-inflicted disease"



Breathlessness was the most feared physical symptom by both patients and carers

Patients reported a loss in independence in daily life and spouses underlined the social isolation of the couple

Patients reported a feeling of discrimination by healthcare professionals regarding their smoking habit

Both patients and carers underpinned the importance of a multidimensional and multiprofessional care, which is lacking

Both patients and carers underlined the importance of sharing experiences with peers to raise awareness and improve caretaking

Conclusions

Improving communications skills on addressing smoking behaviour in COPD patients may reduce the perception of discrimination and strengthen the therapeutic relationship

These findings informed a collaborative inquiry group as part of an action research project which aims to develop new ways to integrate palliative care in advanced COPD

For more information contact Tanja Fusi-Schmidhauser
t.fusi@lancaster.ac.uk tanja.fusi-schmidhauser@eoc.ch