



Opinion

The social and lifestyle impact of COPD

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is one of the world's most disabling non-communicable health problems.¹ The prevalence of COPD is estimated at about 4-5% and yet only about a third have yet been diagnosed. So for an average GP practice list of approximately 1,800, there may be as many as 90 patients with the condition, but only about 30 with a confirmed diagnosis. Both mortality and morbidity are increasing¹ and it is now recognised that the condition is equally prevalent in people under the age of 65 years of age as those over.² The social and lifestyle impact on the individual living with the condition and their families will be dependent on a multitude of factors such as disease severity, age, existence of co-morbidities and family and social support systems. Some will experience a gradual loss of independence, while others will be more profoundly affected at an earlier stage of the disease pathway.

A British Lung Foundation³ survey found that patients focus on how unwell they feel, their ability to perform everyday activities and on the emotional consequences of the disease. Healthcare professionals, on the other hand, tend to focus on physical functioning and measuring clinical outcomes. These divergent perspectives need to be explored during consultations.

Social Impact

In addition to having an impact on a person's quality-of-life, loss of activity can have an economic impact at both a personal and family level and also a societal level.^{4,5} An international study of the impact of COPD on a working age population⁵ revealed that loss of income worried those both still in work and those not working. 44% [n: 314] of those still employed expressed concern about the consequences of COPD on their future earning capacity. 37% [n: 896/2426] of all respondents reported that their total income had decreased as a consequence of their COPD, of which 80% [n: 719] indicated that this had a negative effect on their lifestyle. This resulted in uncertainty and anxiety about their future and that of their families. Income may be reduced as individuals take time off paid work, or reduce their hours or some may need to retire prematurely. This will inevitably have both an

emotional and financial impact on them and their family members and restrict them in terms of achieving their life goals, planning their retirement.

It is important to ask people about the impact their condition is having on their employment. It may be appropriate to contact employers or the occupational health department to suggest the individual changes their job function or their hours of work, in order to keep them in employment for longer.

"I can't work, I can't get a job, I can't get in my garden and I've not many pleasures left so I am not going to change...nothing is a pleasure now"

Physical Limitations

Fatigue resulting from COPD and dyspnoea does not only limit physical activity, but in turn can impact on day to day ability to socialise.^{4,6} Patients who feel breathless often become anxious and many adapt their lifestyles to reduce the level of breathlessness. This becomes a cycle of decline as people become less active, their muscles decondition and they find it increasingly difficult to be active. Encouraging patients to stay active can optimise their overall health status and help them stay positive. Referral to pulmonary rehabilitation can provide them with the support to achieve this.

"I am envying people who manage to do things and I am sitting thinking to myself: five years ago you could do that. You can't picture ever being able to do it again, you never"

Quality of Life

The goals of treatment for chronic disease are to diminish the burden on the patient and to prevent or slow down disease progression. People with COPD have reduced quality of life in comparison to available population norms, using the EQ5D as a measure.⁵ Women with COPD have been reported to have lower quality of life than men with COPD.⁷

Patients have to integrate their COPD into their everyday life; so periodic assess-

ments of patients' quality of life should be performed as part of a comprehensive package of care. A more specific and focused approach to ascertaining the impact of their condition on quality of life might lead to a better tailoring of care to individual needs. It is important that the patients present their own perceived health-related quality of life, as this may differ substantially from the health care professionals' perception of the impact of the disease on the individual. The use of validated assessment tools in the consultation help to focus the health care professional's attention to the patients' true needs and can stimulate tailored interventions.⁸ The Clinical COPD Questionnaire (CCQ) (Available from <http://www.ccq.nl>) and the COPD Assessment Test (CAT) (available from <http://www.catestonline.org>) are simple, quick and easy to use assessment tools which may assist with eliciting the impact of COPD on the patient.

"Some days are a lot worse than others! It does get frustrating sitting here, day after day"

Psychological problems

COPD symptoms and the subsequent effects on lifestyle can have a psychological impact: people with COPD frequently experience feelings of anxiety, and depression.^{9,10} People with COPD, who suffer from depression and/or anxiety, are at a higher risk for COPD exacerbations, so it is important that mental health problems are detected early and treated appropriately. There are several validated instruments available for assessing psychological morbidity. Some are generic instruments and not specifically for respiratory patients but nevertheless they are really helpful in identifying patients with psychological problems, these include the Hospital Anxiety and Depression score (HADS) (Available from <http://www.gl-assessment.co.uk/products/hospital-anxiety-and-depression-scale-0>) and the Patient Health Questionnaire (PHQ9) (Available from <http://www.phqscreeners.com>) which is a simple, validated and easy to use tool. The COPD Assessment Tool Score, although not constructed with a specific domain related to depression can often lead to the detection

of such problems though the dialogue during the consultation.

Interventions such as relaxation techniques, Cognitive Behavioural Therapy and simple goal setting can support patients with psychological problems, either in combination with or instead of pharmacological treatments. It may be appropriate to refer to a psychological therapist.

As smoking is a major cause of COPD, many patients experience stigma, which in turn can have profound effect on social interactions. Family members may feel angry because of the perceived "self-inflicted" nature of the condition and this can impact negatively on family dynamics. For the patient there may be feelings of guilt, low self-esteem and embarrassment which will impact on their confidence.

"The practice nurse seems to think that I should go onto anti-depressants I said I don't want to go onto anti-depressants because I am not depressed I am lonely and I am fed up and weary I said that's all"

Impact on Family and Carers

Because of the chronic nature of the disease and disabling symptoms associated with it, families and friends often feel obliged to take on considerable physical, social and emotional responsibilities when caring for people with COPD.¹¹

It is important that there is support for the whole family and including carers in consultations, with the patients' agreement, can allow healthcare workers to meet the medical and psychological needs. This may be in the form of counselling, respite or support groups such as the British Lung Foundation 'Breathe Easy' Group, of which are available across the country. www.blf.org.uk/BreatheEasy

"Well yes it's true that not a lot of people understand really, you say your husband's short of breath, oh that's a pity, that's a shame. They don't really know the impact on your life, it is a big, big impact on your life"

What else can primary care clinicians do?

The range of factors influencing the management and outcomes of COPD is greater than is often appreciated. The social and lifestyle

Box 1. Practical help

- **Education:** It is important for patients, carers and family members to learn as much as they can about COPD. COPD is a family disease, and the more the family knows, the more they can help and offer support. It is important that education strategies are geared to enabling patients to self-manage.
- **Pulmonary Rehabilitation /Exercise Referral schemes:** Patients should be referred to pulmonary rehabilitation as a matter of course.
- **Communication:** Encourage patients to share their emotions with friends and family as it helps to get feelings out in the open and it helps loved ones understand their behaviour.
- Encourage patients to talk about how they are feeling about COPD and the difficulties they be experiencing coping on a day to day basis. Interventions such as **Cognitive Behavioural Therapy** can be helpful as can pharmacological interventions.
- **COPD support groups:** Joining a COPD support group such as a British Lung Foundation Breathe Easy Group can be a great way to get emotional support from people who really understand what patients and their loved ones are going through www.lunguk.org
- **Financial support:** Information about benefits available for people with COPD is available from the NHS Choices website www.nhs.uk, British Lung Foundation www.lunguk.org, Government benefits <https://www.gov.uk/browse/benefits>, Citizens Advice Bureau <http://www.citizensadvice.org.uk>, Carers Direct <http://www.nhs.uk/CarersDirect/Pages/CarersDirectHome.aspx>

impact on people with COPD, their family and carers is multifactorial, extensive and potentially under-recognised.

Supporting patients through the various stages of their disease and the psychological impact that may have on both the individual themselves and their family members, is an important role for primary care practitioners and is equally as important as treating the physical condition. Primary healthcare practitioners need to consider the wider impact of COPD and the complexity of its management alongside co-morbidities. This can be achieved by employing a wide ranging and holistic approach.

Living with COPD presents patients with many challenges, but while some people view a life with COPD solely in terms of limitations, others will still see new possibilities. Many people and their families are able to make decisions and lead fulfilling lives by adjusting their lifestyles, replacing the activities they can no longer enjoy with new ones.

"It's a Nintendo, ... tests your brain, keeps your brain, gives you a lot of puzzles to solve and everything. It's quite interesting. But the grandchildren.... When they're back up the next time we'll say, right, come on let's see how good you are now! It's quite interesting, you can do a lot of things"

The quotes are from patient participants in the 'Breath of Fresh Air' study. Pinnock H, Kendall M, Murray S, Worth A, Levack P, Porter M, MacNee W, Sheikh A. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ* 2011; **342**:d142

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Editor: Hilary Pinnock, University of Edinburgh

Registered Address: PCRS-UK, Unit 2 Warwick House, Kingsbury Road, Curdworth, Sutton Coldfield B76 9EE **Telephone:** +44 (0)1675 477600
Facsimile: +44 (0)121 336 1914 **Websites:** <http://www.pcrs-uk.org>, <http://www.thepcrj.com> **Email:** info@pcrs-uk.org

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