

# **Living with COPD: understanding patients' experiences as first step to holistic care**

## **Introduction**

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Life expectancy in the UK has been steadily rising over the last five decades. Meanwhile, the number of years lived without disability has failed to increase accordingly.<sup>1</sup> Chronic, life-limiting conditions have replaced infectious diseases as the leading cause of death worldwide, causing a large proportion of the population to spend their last years suffering from an heavy disease burden and markedly decreased quality of life.<sup>2</sup> Such patients have unique care requirements, encompassing complex psychosocial needs in addition to strictly physical complaints.

Each chronic condition comes with a particular set of challenges. This essay will focus on the example of chronic obstructive pulmonary disease (COPD). COPD is presently estimated to affect 3 million people in the UK, two thirds of whom are undiagnosed.<sup>3,4</sup> It is currently the third leading cause of death worldwide<sup>5</sup> and its prevalence remains on the rise.<sup>6</sup> With such an immense burden of disease, it is necessary for health care professionals to understand the experiences of COPD sufferers in order to provide comprehensive and compassionate care for their patients.

To this aim, this essay will draw on the experiences of COPD patients to explore the reality of living with a terminal illness. Further, it will discuss the demands that chronic diseases impose on the relationship between patients and their health care providers, with particular emphasis on the breakdown of communication regarding disease course and progression as a barrier to provision of high quality care. In addition to examples from literature, this essay is based on conversations with Mr Johnson\*, a 76-year-old COPD sufferer who was first diagnosed with the condition over a decade ago.

## **Psychological impact of living with a chronic condition**

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Understanding patients' perception of their illness is an important first step to providing comprehensive, multifaceted care for chronic disease sufferers. The following section will examine main themes derived from patients' accounts of their experience of living with COPD as a life-limiting illness.

### **Social implications**

In a meta-synthesis of qualitative research on experiences of COPD patients, one of the recurring themes was the experience of social isolation.<sup>7</sup> Due to the persistent dyspnoea and fatigue, patients are usually confined to their houses. Researchers conducted interviews regarding the end-stage of the disease with carers and close ones after the patients had died, and found out that 40% of the deceased patients had left the house less than once a month or not at all in the last year of life.<sup>8</sup> In another study, patients reported that their dyspnoea was the main reason for their reluctance to leave the house – partly as they felt they could not cope with

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\* *Pseudonym*

the physical strain, and partly due to the conspicuousness of their symptoms, which often attracted unwanted attention.<sup>9</sup>

Mr Johnson often reminisces about his days as a milkman, when he used to be “out and about”, walking and driving around the neighbourhood all day. At present, his disease significantly impairs his physical mobility. On one occasion, when working in the garden, he suffered an attack of breathlessness so severe he had to crawl back to the house as he was unable to walk. Incidents such as this one left him anxious to leave the house. In Mr Johnson’s case, the progression of his disease coincided with his retirement, the move to a new area and the death of his sister, all of which have contributed to his feeling of social isolation. His social circle has shrunk and the only person he sees on a daily basis is his wife. In his experience, such isolation is one of the most devastating implications of the disease. This impression is common among other patients; in one study, poor quality of life reported by patients (only 33/100 using a subjective scoring system) was found to correlate particularly strongly with low level of social functioning.<sup>10</sup>

In addition to the physical lack of mobility, patients’ illness is associated with changing roles and responsibilities in the society. One patient described it as a “change of lifestyle completely from a doer to a non-doer”.<sup>11</sup> Additionally, the increased symptom burden brings with it “a complete loss of personal liberty” and independence.<sup>11</sup> As a consequence, the patients come to rely on their caregivers, most often spouses, which profoundly changes the dynamic of their relationship. Mr Johnson often emphasizes that his wife, his primary caregiver, worries about him too much, and that she is sacrificing her own health to care for him and the household. He perceives this state of affairs as a disruption of the norm – as a stereotypical “man of the house”, he has grown used to being in charge. Therefore, his current dependence on his wife changes and undermines his perception of himself as a husband and the primary provider for the family.

### **Uncertainty about the future**

In the experience of many patients their disease has deprived them of the future they had planned.<sup>8</sup> This perceived loss was especially important to Mr Johnson. Before he fell ill, he and his wife enjoyed travelling around the Mediterranean area. Having visited multiple countries and islands, including mainland Greece, Italy, Spain, Egypt, Corfu and Cyprus. Mr Johnson remains fascinated with the culture and history of the region. He refers to Cyprus as “his place in the sun”, where he had planned to purchase a small house to spend his retirement years in. Due to his illness, Mr Johnson cannot travel anymore – his last attempt resulted in an emergency hospitalisation. Mr Johnson does not seem to acknowledge his health might not permit him to travel again and expresses his hope for an imminent improvement of his condition. This reluctance to think about the progression of the disease is shared by many other patients, who admit they prefer not to “look to the future” and instead concentrate on the day-to-day. Some have given up hope altogether, saying: “I haven’t got any future”.<sup>12</sup>

### **Feelings of guilt due to self-inflicted disease**

A theme especially pertinent to COPD is the psychological burden of self-inflicted disease. Although lifestyle choices constitute a significant risk factor for most of the prevalent chronic diseases, few links are as strong and widely known as the association between smoking and COPD, where some 90% of cases are attributed to smoking (although recent research indicates that figure may be a vast overestimation).<sup>13</sup> In a study on experiences of self-blame in COPD patients, participants reported a “terrible feeling of guilt” and social stigma.<sup>14</sup>

Misunderstanding of addiction as “character failure” and recklessness contributes to the feelings of shame.<sup>14</sup> I believe this misconception may be fuelled by the emphasis of health care practitioners on smoking cessation advice, which, while proven successful in improving patients’ outcomes,<sup>15</sup> may reinforce their feelings of guilt. This, in turn, may have serious implications to the patients’ experience of disease, including further social withdrawal and reluctance to seek help and treatment. This tendency is evident in interviews with patients, who often believe that “it’s not worth complaining, because I have caused it myself.”<sup>16</sup>

Although he never explicitly admitted to feeling shame or guilt, Mr Johnson often raised the topic of smoking in our conversations. He mentioned that when he first started smoking, “the times were different” and the risks unknown; he also emphasized that he had given up smoking as soon as he received his diagnosis and remained cigarette-free ever since. He also expressed his frustration with the fact that despite his giving up the habit, the disease progressed nonetheless – thus indirectly affirming the view of COPD as a consequence or even punishment for smoking.

### **Anxiety and depression**

Rates of anxiety and depression are consistently higher in chronic disease sufferers compared to the general population.<sup>17</sup> Among COPD patients, it is estimated that one in four has clinically significant depression, which corresponds to approximately double the prevalence in the general population.<sup>18</sup> Similarly, the prevalence of clinically relevant anxiety is increased two-fold in COPD patients compared with a control group.<sup>19</sup> Gore and colleagues report that in the end-stage of disease, 90% of patients are found to have either anxiety or depression.<sup>20</sup>

High rates of anxiety and depression are not surprising in light of poor social functioning, uncertainty about the future, and feelings of shame and guilt experienced by the patients. I believe that an additional contributing factor in case of COPD relates to the strong association between anxiety and breathlessness, one of the major symptoms of COPD. The psychological impact of dyspnoea is enormous. Patients described it as “very claustrophobic” and “frightening”.<sup>11</sup> Bailey<sup>21</sup> describes the “anxiety-dyspnoea-anxiety” cycle experienced by COPD patients, whereby the feeling of shortness of breath provokes severe anxiety which in turn further exacerbates the breathlessness. The existence of this circular causality, which falls in line with the biopsychosocial model<sup>22</sup> of disease, emphasizes the importance of breaking the cycle and treating the mood disorders appropriately before they contribute further to the patients’ symptom burden.

Disappointingly, mood disorders are some of the most undertreated COPD symptoms. A study of nearly four hundred patients reported that while 77% experienced low mood, it was only successfully treated in 8% of cases.<sup>8</sup> This failure certainly does not stem from lack of available treatment options. Both tricyclic antidepressants and selective serotonin reuptake inhibitors (SSRIs) have been found to improve symptoms of depression and anxiety in COPD patients.<sup>6</sup> Other studies demonstrate that self-management techniques related to tackling negative emotions and cognitions of the patients, including cognitive-behavioural therapy, relaxation techniques, group therapy sessions and others, consistently yield positive effects on patients’ perception of their disease, ability to cope with stress, and overall perceived quality of life.<sup>23</sup> Despite such positive results, self-management skills are rarely taught to COPD patients, with usual consultations retaining focus on the management of physical symptoms.<sup>23</sup> I believe that to be a flawed approach. Particularly in case of incurable conditions such as COPD,

psychological help and relief of physical discomfort are of equal importance and should both feature in any comprehensive care plan to ensure patients' wellbeing.

### **Patients' understanding of their condition**

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Having discussed the psychological burden of living with COPD, this section will analyse patients' attitudes and understanding of their disease. In my discussions with Mr Johnson, it soon became apparent that he did not fully understand the nature of his disease or the prognosis. When we first met, he remarked that I probably knew a lot more about his condition than he did. However, it was not for the lack of curiosity – he often asked medical questions, inquiring about details of lung function or pathophysiology of diseases (“I have always wondered what it means to have a heart attack – does the heart just stop?”). I sensed he had been wondering for years - but never asked, perhaps embarrassed to appear ignorant or waste doctors' time.

As indicated by other COPD patients, discussions with health professionals about their disease are seldom exhaustive (“We were just told this is what you've got, get on with it”<sup>24</sup>). One study of patients with severe or moderate COPD in England indicated poor awareness of the diagnosis: out of twenty-one patients, four thought they had asthma, and four did not know the reason for their symptoms at all. Further confusion amongst the patients has been reported to result from the effects of the disease becoming conflated with the normal process of aging.<sup>7</sup> Out of the patients who were aware of the diagnosis, most were unable to describe the disease in any detail.<sup>25</sup> Furthermore, they were not conscious of the implications and prognosis of the disease: only a minority knew the condition could get worse or that it can lead to death. None of the patients reported having discussed the likelihood of death with their health care provider. The patients were mostly aware of their poor understanding and reported that they would welcome further discussion and more information.<sup>25</sup>

With three hospitalisations in the last year and occasionally needing supplemental oxygen therapy, Mr Johnson was in the end-stage of his disease. Yet this was never communicated to him. None of the health care professionals he had seen in the recent months, either in the hospital or the GP practice, have discussed with him the fact that his disease had likely progressed to an irreversible stage. In fact, he expected to soon recover enough to be able to travel independently. Was this omission really in his best interest? Although difficult to communicate, I believe it is absolutely essential that health care professionals do not allow their patients to remain unaware of their prognosis. Withholding this information deprives the patients of a chance to come to terms with their condition, leading to feelings of disappointment, frustration, or even guilt at the unexpected deterioration. Although the temptation to provide reassurance and (false) hope is understandable, it is ultimately not in the patients' best interest.

### **Doctor-patient relationship in the context of life-limiting illness**

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The doctor-patient relationship in the context of chronic disease is subject to unique demands and challenges. The reality of untreatable illness can threaten or disappoint the doctors themselves –in modern medicine, success is often equated with cure, and any efforts that do not produce a curative outcome can be regarded as futile. This can produce feelings of frustration towards patients who cannot be cured.<sup>26</sup> Especially in primary care, chronic conditions may also transform the interactions between the doctor and the patient from strictly disease-centric, short consultations into a years-long relationship, in which the doctor must

satisfy patient's social and psychological needs in addition to treating their physical ones. Additionally, purely pragmatic concerns come into play – when treating a person with a chronic condition, particularly with multiple comorbidities, clinicians may deal with shortage of time and resources to address all their needs.

Especially towards the end of life, good quality care relies on effective and honest communication between doctors and their patients.<sup>27</sup> NICE guidelines regarding services for COPD patients advise that the patients should be provided with palliative treatments to relieve the symptoms;<sup>3</sup> additionally, they advise that the “end of life strategy”<sup>28</sup> should be implemented for COPD patients in advanced stage of their disease, so that they are offered a say in their advance care planning. This include their preferred environment in which they wish to spend their last days as well as any interventions, such as mechanical ventilation, that they may not wish to be subjected to. In practice, these discussions seldom happen.

In a series of interviews with professionals who work with patients with life-limiting illnesses, it was found that while they recognise that patients and their caregivers should be told the truth about the prognosis, in practice these conversations were rarely held. Healthcare workers cited stress, time constraints, perceived lack of expertise in dealing with psychological issues, and unpredictable trajectory of disease as reasons for avoiding conversations about end of life care with patients. Additionally, they worried such discussion would have negative impact on the patients, and that their inability to provide further treatment or cure would be perceived by the patients as a failure on their behalf.<sup>29</sup>

Inadequate communication resulting from strained doctor-patient relationship may contribute to poor outcomes, including insufficient palliative and end-of-life services being offered to the patients. This may be particularly significant in COPD – as cited above, patients often feel that they do not deserve treatment or medical attention and are isolated socially to the point they may be unable to actively seek help. Therefore, it is particularly important for the physicians to initiate such discussions with their patients, even if they find them difficult. At present, patients report that services they receive tend to be focused on the management of acute exacerbations instead of the provision of comprehensive, holistic care.<sup>10</sup> The doctors' reluctance to discuss disease prognosis and appropriateness of palliative care certainly contributes to this state of affairs. The breakdown of communication could also be responsible for the poor provision of psychological support and therapy to COPD patients as discussed above.

## **Conclusion and future directions**

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As a life-limiting condition, COPD is associated not only with a number of physical symptoms, but also a significant psychological burden. This essay identified social isolation and change of social roles, anxiety about the future, and feelings of guilt over self-inflicted disease as major themes in patients' experience. These all come together to produce alarming rates of clinically significant anxiety and depression among patients who rarely receive treatment for their mood disorders.

The reality of living with chronic disease affects patients in all domains of life, including the relationships and conversations with their health care providers. Main barriers to effective communication on behalf of doctors were identified to include the uncertain course of the disease, lack of appropriate mental health training and worry about negative impact on the patients. In addition, COPD patients were recognised as generally reluctant to seek help. In

many cases, the discussions between the patients and their doctors seem to place emphasis on the management of current crises rather than long-term care. As a result, patients' understanding of their disease and prognosis, as well as palliative services they are offered, remains inadequate.

In order to meet the complex needs of the growing population of COPD patients, the barriers in communication between the patients and their health care providers must be broken. If hesitant to initiate such difficult and emotional discussions, health care professionals are advised to refer to clinical practice guidelines for communicating prognosis and end-of-life issues,<sup>30</sup> which recognise the challenges and offer strategies for managing these conversations. Only in such context can the needs of the patients be learned and addressed, and their quality of life improved.

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## Bibliography

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1. Jagger C. Trends in life expectancy and healthy life expectancy. Foresight, Government Office for Science. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/464275/gs-15-13-future-ageing-trends-life-expectancy-er12.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/464275/gs-15-13-future-ageing-trends-life-expectancy-er12.pdf). Published 2015. Accessed April 3, 2016.
2. Cleary AS. Integrating palliative care into primary care for patients with chronic, life-limiting conditions. *Nurse Pract.* 2016; 41(3):42-48.
3. National Institute for Health and Care Excellence (NICE). *Services for People with COPD: Commissioning Guide*. <http://www.nice.org.uk/guidance/cm43>. Published October 1, 2011. Accessed April 3, 2016.
4. National Institute for Health and Care Excellence (NICE). *Chronic Obstructive Pulmonary Disease in Adults*. <https://www.nice.org.uk/guidance/qs10>. Published July 28, 2011. Accessed April 3, 2016.
5. Terzikhan N, Verhamme KMC, Hofman A, Stricker BH, Brusselle GG, Lahousse L. Prevalence and incidence of COPD in smokers and non-smokers: the Rotterdam Study. *Eur J Epidemiol.* <http://link.springer.com/article/10.1007%2Fs10654-016-0132-z>. Published March 5, 2016. Accessed March 31, 2016.
6. Spathis A, Booth S. End of life care in chronic obstructive pulmonary disease: in search of a good death. *Int J Chron Obstruct Pulmon Dis.* 2008; 3(1):11-29.
7. Disler RT, Green A, Luckett T, et al. Experience of advanced chronic obstructive pulmonary disease: metasynthesis of qualitative research. *J Pain Symptom Manage.* 2014;48(6):1182-1199.
8. Elkington H, White P, Addington-Hall J, Higgs R, Edmonds P. The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliat Med.* 2005;19(6):485-491.
9. Gullick J, Stainton MC. Living with chronic obstructive pulmonary disease: Developing conscious body management in a shrinking life-world. *J Adv Nurs.* 2008;64(6):605-614.
10. Skilbeck J, Mott L, Page H, Smith D, Hjelmeland-Ahmedzai S, Clark D. Palliative care in chronic obstructive airways disease: a needs assessment. *Palliat Med.* 1998;12(4):245-254.
11. Seamark DA, Blake SD, Seamark CJ, Halpin DM. Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. An interpretative phenomenological analysis. *Palliat Med.* 2004;18(7):619-625.
12. Wilson DM, Ross C, Goodridge D, Davis P, Landreville A, Roebuck K. The care needs of community-dwelling seniors suffering from advanced chronic obstructive pulmonary disease. *Can J Aging.* 2008;27(4):347-357.

13. Marsh S, Aldington S, Shirtcliffe P, Weatherall M, Beasley R. Smoking and COPD: What really are the risks? *Eur Respir J*. 2006;28(4):883-884.
14. Halding AG, Heggdal K, Wahl A. Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scand J Caring Sci*. 2011;25(1):100-107.
15. Tashkin DP, Murray RP. Smoking cessation in chronic obstructive pulmonary disease. *Respir Med*. 2009;103(7):963-974.
16. Lindqvist G, Hallberg LR-M. "Feelings of guilt due to self-inflicted disease": a grounded theory of suffering from chronic obstructive pulmonary disease (COPD). *J Health Psychol*. 2010;15(3):456-466.
17. DeJean D, Giacomini M, Vanstone M, Brundisini F. Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ont Health Technol Assess Ser*. 2013;13(16):1-33.
18. Zhang MWB, Ho RCM, Cheung MWL, Fu E, Mak A. Prevalence of depressive symptoms in patients with chronic obstructive pulmonary disease: A systematic review, meta-analysis and meta-regression. *Gen Hosp Psychiatry*. 2011;33(3):217-223.
19. Eisner MD, Blanc PD, Yelin EH, et al. Influence of anxiety on health outcomes in COPD. *Thorax*. 2010;65(3):229-234.
20. Gore JM. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*. 2000;55(12):1000-1006.
21. Bailey PH. The dyspnea-anxiety-dyspnea cycle--COPD patients' stories of breathlessness: "It's scary /when you can't breathe". *Qual Health Res*. 2004;14(6):760-778.
22. Borrell-Carrio F, Suchman A, Epstein R. The biopsychosocial model 25 years later. *Ann Fam Med*. 2004;2(6):576-582.
23. Kaptein AA, Fischer MJ, Scharloo M. Self-management in patients with COPD: theoretical context, content, outcome, and integration into clinical care. *Int J COPD*. 2014;9:907-917.
24. Gysels M, Higginson IJ. The Experience of Breathlessness: The Social Course of Chronic Obstructive Pulmonary Disease. *J Pain Symptom Manage*. 2010;39(3):555-563.
25. Gardiner C, Gott M, Small N, et al. Living with advanced chronic obstructive pulmonary disease: patients concerns regarding death and dying. *Palliat Med*. 2009;23(8):691-697.
26. Campbell C, McGauley G. Doctor-patient relationships in chronic illness: insights



- from forensic psychiatry. *BMJ*. 2005;330(7492):667-670.
27. Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J*. 2008;32(3):796-803.
  28. Richards M. End of Life Care Strategy. Department of Health, London. [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_086345.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf) \n <http://www.crusebereavementcare.org.uk/BPPpapers/EoLCMikeRichards.pdf>. Published July 2008. Accessed March 31, 2016.
  29. Hancock K, Clayton JM, Parker, SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med*. 2016; 21:507-517.
  30. Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust*. 2007;186(12):79-108.