

**Ad A. Kaptein**

Medical Psychology, Leiden University Medical Centre

**Brian M. Hughes**

School of Psychology, National University of Ireland

Chronic obstructive pulmonary disease (COPD) is a chronic, irreversible and progressive respiratory disease characterized by persistent airflow limitation, and associated with an enhanced chronic inflammatory response in the airways and the lungs. What was once diagnosed as chronic bronchitis or emphysema is nowadays classified as COPD. Patients with COPD experience symptoms of shortness of breath (dyspnea), persistent cough and increased sputum production. In daily life, people with COPD are limited in the physical, psychological and social realms of their lives. Chronic obstructive pulmonary disease impacts negatively on patients' wellbeing by incurring anxiety, depression, fatigue, impaired work performance, poor sexual quality of life and limitations in social activities. The wellbeing of the patient's spouse, family and society at large (in terms of disability payments) are also impacted by this illness (Vaske *et al.*, 2015).

The prevalence of COPD is about 8 per cent, with fairly large variations in populations and countries due to differences in epidemiological approaches, operationalization of diagnostic criteria and health care systems (GOLD, 2017). Its prevalence is increasing mainly due to the demographics of tobacco smoking. In industrialized countries, COPD now represents the third leading cause of death (GOLD, 2017). With global patterns of tobacco smoking changing across industrialized and developing countries, disability and death due to COPD will presumably change accordingly. Moreover, with tobacco use by women having escalated after World War II, COPD is no longer a typically male disease. Given the association between smoking and lower socioeconomic status, COPD has also occasionally been labelled a 'working class' disorder (Levinson, 2017).

The earliest studies on patients with COPD had a psychiatric focus. Using the Szondi-test, Webb and Lawton (1961) observed high levels of psychological and psychiatric morbidity in persons with COPD in a rehabilitation setting. In a sample drawn from a third-line hospital for patients with respiratory diseases, Agle *et al.* (1973) observed extensive psychiatric and behavioural problems associated with severe COPD. In fact, anxiety and depression had an almost 100 per cent prevalence, in addition to high levels of alcoholism, sexual dysfunction and psychiatric problems. In contrast to patients with asthma, where psychosomatic theorizing led to victim-blaming (often directed at mothers of children with asthma), patients with COPD were fortunately not the object of psychiatrically inspired views about causes of respiratory disorders (Chapter 98). Implicitly or explicitly blaming the patients for their smoking behaviour causing their illness, however, is quite prevalent (see Kaptein *et al.* (2009) for further discussion of this issue in a concise history of behavioural research on COPD).

Studies on the neuropsychological consequences of COPD have opened up the area of behavioural research in patients with chronic respiratory disease. Neuropsychological assessments of patients with severe COPD showed major negative consequences in various domains

of neuro-psychological functioning, such as memory and cognitive problems. Compared to non-COPD controls, patients with COPD in a rehabilitation setting exhibited general cognitive impairment (14 vs. 60 per cent, respectively), as well as deficits in psychomotor speed, planning and cognitive flexibility (Cleutjens *et al.*, 2017; see Schou *et al.*, 2012, for a systematic review). Reduced oxygenation of the brain is the most likely determinant of these dysfunctions, making the administration of extra oxygen a desirable intervention method. Daily oxygen therapy, for 16 or 24 hours a day, is a part of life for some COPD patients but, notwithstanding its frequent depiction in media and cultural portrayals of COPD, only a small minority (~1–2 per cent) are prescribed this form of treatment (Ringbaek, & Lange, 2014).

Neuropsychological studies showed how the consequences of COPD for the lives of patients could extend far more broadly than what was expressed in respiratory symptoms alone. This inspired psychologists, in collaboration with physicians and nurses, to explore the experiential aspects of COPD in more detail, laying the groundwork for research on quality of life. Questionnaires to assess disease-specific quality of life in people with COPD are now almost routine in clinical studies. Two of the most used are the CRQ (Chronic Respiratory Questionnaire; Guyatt *et al.*, 1987) and SGRQ (St. George's Respiratory Questionnaire; Jones *et al.*, 1992). The CRQ assesses the dimensions of 'dyspnea', 'fatigue', 'emotional function' and 'mastery'. Including the domains 'mastery' and 'emotional function' in a quality of life measure demonstrates how successfully psychology has become embedded within COPD research and clinical management. The SGRQ assesses symptoms, activity and impacts, also demonstrating the relevance of psychology in clinical care and research on persons with COPD. Overall, the lack of success to fully explain quality of life scores using only biomedical data, such as pulmonary function, has offered psychologists the opportunity to establish a domain of expertise in the world of respiratory medicine.

The early 1980s saw psychological research in patients with COPD begin in earnest. As COPD impairs activities of daily living, attempts to reduce these impairments were explored. In a randomized controlled trial comparing five conditions, Atkins *et al.* (1984) examined exercise capacity and its psychological concomitants. In the experimental condition with the strongest intervention (i.e. addressing and changing cognitions regarding the respiratory condition), patients' illness perceptions were identified, addressed and replaced with more adaptive cognitions. For example, participants were taught to replace self-statements such as 'I can't walk very far without getting short of breath, so what's the use?' with ones such as 'This walking is uncomfortable, but I can handle it. Soon I will be able to walk farther' (p. 594). This study is crucial in the COPD area as it was the first to demonstrate how addressing COPD patients' illness perceptions can improve both functional status and quality of life. In another study (Kinsman *et al.*, 1983), patients'

subjective symptomatology was found to be independent of objective measures such as pulmonary function, further encouraging respiratory clinicians to incorporate patients' emotions and cognitions into clinical care.

Elements explored in the work described above became incorporated into a new clinical care approach in this context, in the form of pulmonary rehabilitation programmes. Defined as 'an evidence-based, multi-disciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities' (Nici *et al.*, 2006), the first such programmes started out as rather biomedical interventions, aimed at stimulating physical activity. They typically aimed to: 1) facilitate smoking cessation; 2) optimise pharmacotherapy; 3) assist with early identification and treatment of acute exacerbations; 4) manage acute dyspnoea; 5) increase physical activity; 6) improve body composition; 7) promote mental health; 8) facilitate advance care planning; and 9) establish social support networks' (Hill *et al.*, 2013: 405).

Only recently have psychological interventions, aimed at psychological outcomes in particular, managed to attain the status traditionally given to more biomedically oriented programmes (Scharloo & Kaptein, 2003). The psychological components of pulmonary rehabilitation programmes usually focus on self-management training, addressing areas such as coping, illness perceptions, self-monitoring of symptoms, action plans, emergency treatment, lifestyle change (relating to exercise and smoking) and social interaction (Jonkman *et al.*, 2016; Kaptein *et al.*, 2008). Self-management, therefore, is part of the arsenal deployed by behavioural scientists in COPD care and research. Effect studies show that 'pulmonary rehabilitation relieves dyspnea and fatigue, improves emotional function and enhances the sense of control that individuals have over

their condition. These improvements are moderately large and clinically significant' (McCarthy *et al.*, 2015: 2; see also Kaptein *et al.*, 2014). Overall, disease management, typically defined as 'an approach to patient care that emphasizes coordinated, comprehensive care along the continuum of disease and across health care delivery systems', seems a valuable strategy in care for patients with COPD (Peytremann-Bideveaux *et al.*, 2008).

A number of interventions have targeted smoking cessation. Tobacco smoking significantly exacerbates the development of COPD; as such, smoking cessation can make a major contribution to the improvement of COPD in those already affected. Psychologists are instrumental in helping people with COPD give up smoking (Bartlett *et al.*, 2014). If tobacco smoking were to be eliminated from the population, prevalence of COPD would drop very substantially. Nonetheless, two caveats are worth bearing in mind: not all smokers develop COPD, and not every patient with COPD is or has been a smoker.

Breathing is a central biological function that occurs throughout life. When healthy, it may be so familiar as to be taken for granted. As such, when respiration becomes debilitated, the experience of patients can be at once all-encompassing and yet difficult to effectively describe. A small number of studies have suggested that asking COPD patients to produce drawings of their illness may have therapeutic value, within the context of medical care (Luthy *et al.*, 2013). Second, studying how COPD is represented in novels, films, music and paintings may be instrumental in helping clinicians and the public at large empathize with COPD patients and better understand their lived experience (Kaptein *et al.*, 2015). Given the relatively high prevalence of COPD and its major impact on the lives of those afflicted, care that integrates medical and behavioural expertise seems the wisest approach in order to help persons with COPD.

## REFERENCES

- Agle, D. P., Baum, G. L., Chester, E. H. & Wendt, M.** (1973). Multidiscipline treatment of chronic pulmonary insufficiency: 1. Psychologic aspects of rehabilitation. *Psychosomatic Medicine*, **35**, 41–49.
- Atkins, C. J., Kaplan, R. M., Timms, R. M., Reinsch, S. & Lofback, K.** (1984). Behavioral exercise programs in the management of chronic obstructive pulmonary disease. *Journal of Consulting and Clinical Psychology*, **52**, 591–603.
- Bartlett, Y. K., Sheeran, P. & Hawley, M. S.** (2014). Effective behaviour change techniques in smoking cessation interventions for people with chronic obstructive pulmonary disease: a meta-analysis. *British Journal of Health Psychology*, **19**, 181–203.
- Cleutjens, F. A. H. M., Franssen, F. M. E., Spruit, M. A., et al.** (2017). Domain-specific cognitive impairment in patients with COPD and control subjects. *International Journal of COPD*, **12**, 1–11.
- GOLD (Global initiative for chronic Obstructive Lung Disease)** (2017). *Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease*. Bethesda, MD: NIH.
- Guyatt, G. H., Berman, L. B., Townsend, M., et al.** (1987). A measure of quality of life for clinical trials in chronic lung disease. *Thorax*, **42**, 773–778.
- Hill, K., Vogiatzis, I. & Burtin, C.** (2013). The importance of pulmonary rehabilitation, other than exercise training, in COPD. *European Respiratory Review*, **22**, 405–413.
- Jones, P. W., Quirk, F. H., Baveystock, C. M. & Littlejohns, P. A.** (1992). Self-complete measure of health status for chronic airflow limitation. *American Review of Respiratory Disease*, **145**, 1321–1327.
- Jonkman, N. H., Schuurmans, M. J., Groenewold, R. H. H., Hoes, A. W. & Trappenburg, J. C. A.** (2016). Identifying components of self-management interventions that improve health-related quality of life in chronically ill patients: systematic review and meta-regression analysis. *Patient Education and Counseling*, **99**, 1078–1098.
- Kaptein, A. A., Scharloo, M., Fischer, M. J., et al.** (2009). 50 years of psychological research on patients with COPD: road to ruin or highway to heaven? *Respiratory Medicine*, **103**, 3–11.
- Kaptein, A. A., Scharloo, M., Fischer, M. J., et al.** (2008). Illness perceptions and COPD: an emerging field for COPD patient management. *Journal of Asthma*, **45**, 625–629.
- Kaptein, A. A., Fischer, M. J. & Scharloo, M.** (2014). Self-management in patients with COPD: theoretical context, content, outcomes, and integration into clinical care. *International Journal of COPD*, **9**, 907–917.
- Kaptein, A. A., Meulenbergh, F. & Smyth, J. M.** (2015). A breath of fresh air: images of respiratory illness in novels, poems, films, music and paintings. *Journal of Health Psychology*, **20**, 246–258.
- Kinsman, R. A., Yaroush, R. A., Fernandez, E., et al.** (1983). Symptoms and experiences in chronic bronchitis and emphysema. *Chest*, **83**, 755–761.
- Levinson, A. H.** (2017). Where the U.S. tobacco epidemic still rages: most remaining smokers have lower socioeconomic status. *Journal of Health Care for the Poor and Underserved*, **28**, 100–107.
- Luthy, C., Cedraschi, C., Pasquina, P., et al.** (2013). Perception of chronic respiratory impairment in patients' drawings. *Journal of Rehabilitation Medicine*, **45**, 694–700.
- McCarthy, B., Casey, D., Devane, D., et al.** (2015). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, **2**, CD003793.
- Nici, L., Donner, C., Wouters, E., et al.** (2006). ATS/ERS statement on pulmonary

rehabilitation. *American Journal of Respiratory and Critical Care Medicine*, **173**, 1390–1413.

Peytremann-Bidevaux, I., Staeger, P., Bidevaux, P. O., Ghali, W. A. & Burnand, B. (2008). Effectiveness of chronic obstructive pulmonary disease-management programs: systematic review and meta-analysis. *American Journal of Medicine*, **121**, 433–443.

Ringbaek, T. J. & Lange, P. (2014). Trends in long-term oxygen therapy for COPD in Denmark. *Respiratory Medicine*, **108**, 511–516.

Scharloo, M. & Kaptein, A. A. (2003). Chronic obstructive pulmonary disease: a behavioural medicine approach. In Llewelyn, S. & Kennedy, P. (eds), *Handbook of Clinical Health Psychology* (pp. 155–179). Chichester: Wiley.

Schou, L., Østergaard, B., Rasmussen, L. S., Rydahl-Hansen, S. & Phanareth, K. (2012). Cognitive dysfunction in patients with chronic obstructive pulmonary disease: a systematic review. *Respiratory Medicine*, **106**, 1071–1081.

Vaske, I., Thöne, M. F., Kühl, K., et al. (2015). For better or for worse: a longitudinal study on dyadic coping and quality of life among couples with a partner suffering from COPD. *Journal of Behavioral Medicine*, **38**, 851–862.

Webb, M. W. & Lawton, A. H. (1961). Basic personality traits characteristic of patients with primary obstructive pulmonary emphysema. *Journal of the American Geriatrics Society*, **9**, 590–610.

Elizabeth Ball

Queen Mary University of London, Royal London Hospital

### What is Chronic Pelvic Pain?

Chronic pelvic pain (CPP) can affect both genders, but is more common in women. This chapter will focus on CPP in women, which is defined as intermittent or constant pain in the lower abdomen or pelvis for at least six months, which may or may not be associated with menstruation. In order to fulfil the definition of CPP, complaints should not exclusively be associated with menstruation or sexual intercourse and should occur outside pregnancy.

### Epidemiology and Impact

General practitioners (GPs) in the United Kingdom see as many patients with CPP as with *migraine*, *back pain* and *asthma*. It affects adolescent girls and women during their reproductive years and is less common after the menopause. Women with CPP may be diagnosed and treated by a range of health care professionals such as GPs, psychologists, gastroenterologists, gynaecologists, urologists and physiotherapists. Chronic pelvic pain accounts for 20 per cent of GPs' referrals to gynaecologists (Howard, 2003). Worldwide, estimates suggest that 24 per cent of women suffer from CPP (Latthe *et al.*, 2006).

Many women do not seek medical help because of embarrassment or because friends and family, and even their GPs, tell them that their symptoms are 'normal' (Greene *et al.*, 2009). This can lead to long delays in obtaining a diagnosis and effective treatment.

### What are Common Causes for Chronic Pelvic Pain?

Gynaecological, gastrointestinal, urological, musculoskeletal and neurological and psychological conditions contribute to CPP, which is often a multi-factorial condition. Gynaecological causes account for about 20 per cent of cases.

### Endometriosis

In endometriosis, cells that usually constitute the lining of the uterus are displaced. In their abnormal locations (usually in the pelvis) they produce menstrual bleeding, inflammation and pain. An abnormal nerve supply develops (Berkley *et al.*, 2005). Endometriosis can affect the function of the reproductive system, kidneys and bowels, by causing adhesions between organs, thereby reducing their natural mobility. This adhesion-related pain can further exacerbate pain symptoms.

Pain is typically worse during menstruation and sexual intercourse.

### Pelvic Inflammatory Disease

Another common cause for pelvic pain includes chronic pelvic inflammatory disease, commonly caused by sexually transmitted infections. It is also associated with inflammation and adhesions, in particular with damage to the fallopian tubes.

### Bladder Pain Syndrome

Bladder pain syndrome (previously interstitial cystitis) may coexist with endometriosis (Tirlapur *et al.*, 2013). It is associated with stress, smoking and previous urinary tract infections. Pain occurs especially when the bladder fills up. Patients may experience nightly urinary frequency. It appears to be caused by defects of the protective mucus layer of the bladder, allowing chemical irritants in the urine to seep into the bladder wall.

### Irritable Bowel Syndrome

Irritable bowel syndrome (IBS) is a gastrointestinal pain syndrome that is characterized by chronic or intermittent abdominal pain associated with bowel function. There are no structural changes to the bowel. The