What is the lived experience of patients with COPD?
The aim of this study was to explore and delve into the minutiae of the participant’s experience of living with COPD.

**DESIGN**
A qualitative phenomenological study (Heidegger) was carried out: phenomenology’s focus is on the meaning of experience (Cohen et al, 2000).

**SETTING**
The study setting was a single rural teaching hospital. Participants for the study were purposefully selected from the respiratory outpatient clinics.

**PATIENTS**
The ethics committee granted permission to access eight individuals. The study population were defined as: ‘Individuals diagnosed with severe stage III (GOLD, 2005) chronic obstructive pulmonary disease on optimum medical treatment’.

Stage III is severe COPD, where there is further worsening of the airflow obstruction; the FEV, is now between 30-50% of predicted, there is an increase in symptoms and it now has an impact on the individual’s quality of life.

Individuals with other pulmonary or cardiac problems and/or a diagnosis of a psychiatric illness were excluded. The age range of four men and four women was 36-75 with a mean age of 58.

**METHOD**
Eight participants were interviewed using unstructured interviews. Participants received posted information regarding the study and a consent form. Interview times and locations were agreed. Each participant was audio-taped with their permission, with each interview lasting approximately 90 minutes.

**MAIN FINDINGS**
Three themes were identified, the physical effects of COPD, the psychological effects of COPD and normality. Each theme had sub-themes.
THEME 1 — PHYSICAL EFFECTS OF COPD

1:1 Breathlessness

Breathlessness is a symptom of COPD and was a prominent feature in all of the participants’ daily lives, which in turn had a profound effect on their physical functioning and lifestyle restrictions. One participant explained: ‘bending is a major problem for me, causes shortness of breadth.’ Due to their breathlessness they felt frustrated and tired which then in turn leads to less social activity. The following excerpt is an example of this ‘I just get breathless. I can only walk about 300 yards now, I would have to stop after 300 yards and in 2004 I could walk a mile and a half without (pausing). There is no way in the world I would get around a golf course now.’

The participants also mentioned fear when discussing their breathlessness as this woman explains ‘You see I get awful breathless and then I’m afraid of what’ll happen to me.’ This, therefore highlights the need for a multi disciplinary approach to care as breathlessness affects the individuals physically and psychologically.

1:2 Cough

Throughout the interview process, it was evident that six of the participants had the symptom cough, however they didn’t seem to acknowledge their day to day cough and only discussed what caused them to cough. According to Halpin and Rudolf (2006) many patients have a morning cough, which they regard as normal for them. An excerpt from one participant that portrays this: ‘So (coughs) that was alright…if anyone is cleaning the house I go out the back into the garden, sit down, maybe have a cup of coffee with me so if there is a load of dust, I realise (coughs) why I am doing it. Because I don’t want to get this dust on me chest and start coughing and coughing…i get episodes of coughing but I can usually associate it with a chest infection.’

Most of the participants accepted that their COPD was caused by smoking or related to their occupation. Therefore they didn’t consider their cough a symptom as they related it more to a ‘smoker’s cough.’ Participants associated a cough with being unwell and a flare up of a chest infection. In this study, while many participants spoke about the awareness of a chest infection due to an increase in volume of sputum, none of the participants mentioned the word exacerbation and only one participant spoke about self medicating.

1:3 Fatigue

Fatigue can vary with respect to its daily patterns, triggers or contributing factors, and responsiveness to interventions. Whilst fatigue has been recognised as an important problem for individuals with COPD and is ranked by patients generally as the second most important symptom, relatively little is known about the specific nature of subjective fatigue and its effects on daily life in the COPD population (Kapella et al, 2006). Three of the participants’ reported concerns in relation to fatigue, referring to tiring more easily.

This then raises the issue that if fatigue is the second most important symptom mentioned by individuals with COPD, there needs to be more research into how best to manage this symptom and what options to recommend to individuals with COPD who suffer from fatigue. Results from Kapella et al’s (2006) study suggest a need for further research on symptoms in people with COPD and also to compare fatigue in healthy older people and people with COPD in case fatigue increases with age.

THEME 2: PSYCHOLOGICAL IMPACT OF THEIR ILLNESS

2:1 Fear of the future

Each exacerbation or infection can be perceived as a potential life threat. The uncertainty in the progression of the disease and the unpredictable nature of the attacks of breathlessness can leave many patients fearing this attack could be their last; ‘it’s just the not knowing what tomorrow is going to bring…if I die tomorrow.’

Rather than her disease progressing to the next stage where she may need continuous oxygen, she would rather ‘smoke a thousand cigarettes a day…who would want to live five years on 24 hour oxygen and all that. Why would you want to slow that down?’ (laughs) You’d want to speed that bit up (laughs)

This therefore, has revealed the importance of the nurse patient interaction as this patient attends outpatient clinics regularly and has never highlighted these fears. A multi disciplinary team to review how patients and their families are coping would work well in overcoming this problem.

2:2 A feeling of loss

An area that is linked to the participants’ emotional response to their illness is the feeling of loss of self. There are many losses evident in the transcripts from the participants, from loss of job, loss of hobbies, loss of independence to loss of confidence. One participant describes her experience as follows: ‘I used to be into sports and different things gaelic and I had to give it up…i used to love baking you know there’s days I wouldn’t be able to make a dinner never mind make stand up and make a cake or anything…I can’t even go for a walk’

Another participant experienced a loss of confidence as she explains due to her COPD she doesn’t feel confident in driving alone, she describes her experience by saying: ‘the COPD was hindering me in getting into a car and just driving out which I would be very used to for many a long day, I don’t have he confidence. Do you know before this happened I would drive to Kerry…I wouldn’t dream of that now’.

Studies in relation to COPD and pulmonary rehabilitation demonstrated a heightened sense of control over their COPD resulting in increased confidence and improving their overall emotional wellbeing (Toms & Harrison, 2002; Camp, 2000). No participants in this particular piece of research have been involved in any pulmonary rehabilitation or education programme which leads the writer to the point where pulmonary rehabilitation is the way forward. It will not only improve patients’ psychological outlook on life it may also improve their physical ability, which in turn will increase their independence.

2:3 Guilt

All of the smoking participants felt guilty for smoking and were aware that it caused their COPD, however two continued to smoke. According to the Tobacco Free Policy Review group (2000) quitting smoking is a complex issue for individuals with COPD. The individuals are often not aware of the seriousness of their lung condition until the disease is fairly advanced. The World Health Organisation (WHO) as cited in the Tobacco Free Policy Review Group (2000) has expressed the importance of delivering non-smoking messages through every feasible channel possible. Government officials, public health workers, and the general public should encourage this. A counselling session of three minutes relating to smoking cessation can be effective and should be carried out for each individual at every GP visit by the GP or the practice nurse and such advice and responses to the advice should all be recorded (WHO, 2000). This three minute counselling session should be carried out at each hospital presentation also.
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Moreover, normality surfaced as a key theme consistently. Participants regarded the decline in activities of daily living that healthy individuals take for granted as an effect of COPD. COPD can interrupt the sense of who, where and what an individual believes themselves to be in relation to norms and expectations ascribed by society. This point cannot be underestimated and its salience noted. In this study participants made reference to how their COPD affected all aspects of their normal activities of daily living and thereby dramatically affecting their quality of life.

One participant explained how he is normally a very active man but since he got the oxygen concentrator he doesn’t understand how he will be able to go away for a night, as he is supposed to wear it every night. He sees this machine as a restriction on his social outings and an intrusion into his life.

**CONCLUSION**

Treatment for COPD should include a validated pulmonary rehabilitation programme, yet only a minority of hospitals have this available for their patients. Pulmonary rehabilitation encompasses physical, psychological and psychosocial needs with a multidisciplinary approach. This should be made available to all patients, thereby leading to a more holistic approach to care. This study identified the need for psychological support to be made available during the various stages of COPD as at present there is no psychologist input. The need for patient education and counselling in relation to the illness, the symptoms, the treatment and how to manage an exacerbation has been identified. Occupational therapists can help to reduce fatigue by careful education and a smarter approach to daily activities by teaching patients to pace themselves and conserve energy.

It is important to note that there is no national respiratory strategy set out by the DOHC. A National Respiratory Strategy would ensure that pulmonary rehabilitation is a necessary part of the treatment of COPD and all respiratory multidisciplinary teams throughout the country, are working towards the same goal.

Moreover, there is a gap in the healthcare system between the primary and secondary care system for these individuals. This gap could be filled with the aid of community respiratory nurses or multidisciplinary teams. Initiatives set up in England that allow nurses to manage these patients in their own homes such as the acute chest triage rapid intervention team (ACTRITE) and acute respiratory assessment services (ARAS) have been proven to be beneficial.

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**REFERENCES**


