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Review article

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Experience and prevalence of symptoms among patients living with chronic obstructive pulmonary disease: A review from literature

Omar Melhem, Alexander Gleason, Kavitha Parthasarathy

Assistant Professors, Nursing Department, Fatima College of Health Sciences, United Arab Emirates

*Corresponding Author: Omar Melhem

Email id: Omar.melhem@fchs.ac.ae

ABSTRACT

Background

Patients living with Chronic Obstructive Pulmonary Disease (COPD) experience a complex life situation due to their illness. Understanding their experiences enables the burden of COPD to be recognised by healthcare professionals. Over the past 15 years, there has been a growing interest among researchers to understand the experiences of patients living with COPD.

Objective

This paper explores previous research on symptom experience and prevalence of symptoms among patients living with COPD, and their consequences.

Method

An electronic search strategy was conducted using the following databases: CINAHL, MEDLINE, Academic search complete, Psych INFO, Psych articles, and Psychology and Behavioural Science collection. Scholarly peer reviewed papers published in English between 2000 and 2020 were included. The key words 'experience' or 'living experience' or 'lived experience' or 'symptom experience', 'symptom' or 'symptom prevalence' or 'multiple symptoms', 'chronic obstructive pulmonary disease' or 'COPD' or 'COAD' or 'chronic airway obstruction' or 'chronic airway disease' or 'lung' or 'chest' or 'thoracic' or 'pulmonary' or 'chronic illness' were combined to explore the experience and prevalence of symptoms in patients with COPD.

Results

Eighteen studies met the inclusion criteria. Ten studies were qualitative explored the living experience with COPD including the symptom experience, while 8 cross sectional studies explored the prevalence of many physical and psychological symptoms experienced by patients with COPD.

Keywords: Chronic Obstructive Pulmonary Disease, COPD, Symptoms, Experience, Prevalence

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a chronic, potentially fatal progressive condition of the lungs. The Global Initiative for Chronic

Obstructive Disease (GOLD) has defined COPD as "a common preventable and treatable disease characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and

the lungs to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients” [1].

Much of the research to understand the experience of patients living with COPD has been qualitative in approach, aimed at exploring the ‘lived experiences’ of individuals with COPD including the symptom experience. This paper explores previous research on patients’ lived experiences relating to COPD symptoms, physical and psychological symptoms are considered. Research providing evidence on the negative impact that symptoms can have on patients when living with COPD especially on their functional ability is presented. Furthermore, the prevalence of symptoms among patients with COPD is presented. The literature review presented aims to provide a context of what it is like for individuals to live with COPD symptoms.

Breathlessness

Most of previous research on symptom experience addressed the experience of breathlessness in patients with COPD with fewer studies presenting findings on experiences of other symptoms such as pain, fatigue, and less again on symptoms such as cough and sleep disturbance. Breathlessness has been identified as the most problematic symptom in patients with COPD. In a phenomenological study sampling 14 patients with mild to severe stages of COPD, Avsar and Kasilkcl (2011) explored the experience of living with COPD and how patients were affected by the disease. All patients were experiencing breathlessness, which they described as having a significant impact on them with almost every aspect of their lives being affected [1]. Patients in this study had to make changes in their daily activities due to their worsening breathlessness. The experience of being “alive” for patients meant not being breathless.

Similar findings were evident in a phenomenological study with eight patients with severe COPD by EK and Ternestedt (2008), which found that patients described their health status as “not able to catch their breath”. Difficulty in breathing was the most troublesome symptom experienced which restricted all their daily life activities. Patients also described how their breathing could no longer be taken for granted. This was also described in Gullicks and Stainton’s (2008) Heideggerian phenomenological study with 15

patients with COPD and their family members, which found that patients describe their breathlessness as the beginning of conscious awareness of changes in their bodies. Their breathlessness increasingly limited their self-care abilities, social activities and mobility.

In repeated qualitative interviews using a phenomenological-hermeneutic method over an 8-month period involving 4 patients living alone with severe COPD and long-term oxygen therapy (LTOT), one of the main themes in [9, 10] study was the unpredictable body. Constant breathlessness, which was painful and uncomfortable, was the main symptom experienced by patients. They referred to their bodies as ‘uncontrollable’, the acceleration of their breathing producing a feeling of being controlled by their bodies. As a result, the unpredictable body restricted their daily life activities.

However, patients described the characteristics of their breathlessness as unpredictable and deceptive (Gysels & Higginson 2008; [2]). Patients in these two studies described breathlessness as a symptom that is normally severe and disabling, could be absent at rest and varied from day to day and even hour to hour. In order to understand the effect of the disease on their lives, [13] conducted a hermeneutic phenomenological study with 10 patients with severe COPD. Although some patients described their breathlessness as part of their daily life, the majority of patients had difficulty in finding words to describe the discomfort and the unpleasant nature of the experience of breathlessness.

In structured in-depth interviews, Gysels and Higginson (2011) interviewed 18 patients with COPD, among other patients with chronic illnesses and cancer. Patients with COPD described breathlessness as hardly noticeable in the beginning but developed gradually. They also described how easily they adapted to the restrictions and disability caused by their breathlessness and as they accepted them and they became part of their daily lives. However, in an earlier study using in-depth interviews and observation with 18 patients with COPD, Gysels & Higginson (2010) described how the experience of breathlessness influenced their attitude towards end of life and their quality of life. The onset of dyspnea was described as insidious. Patients initially felt that there was something wrong with their health because of their worsening breathlessness and this was followed by a

deterioration of their health, which led them to seek medical advice.

Other Physical Symptoms

In addition to breathlessness, patients with COPD can experience fatigue. Through semi-structured interviews, [28] conducted a study to explore the experience of fatigue in 20 patients with moderate to severe COPD. Patients described their fatigue as 'overwhelming', and that it was always there, affecting the whole body. Patients in this study experienced an increase in fatigue when they were breathless. Similarly, fatigue was found to affect the body and mind, as described by patients in Ek & Ternstedt's (2008) study. Patients in this study described how they became tired and shaky when their disease moved from a better to a worse period. The strength to handle daily life was affected because of fatigue which made some of them want to commit suicide.

Another symptom experienced by patients with COPD across a number of studies was pain. [25] Interviewed 16 patients with COPD in semi-structured interviews to explore their experience of pain and its impact on their quality of life. Patients were found to have arm, neck, hip, and chest pain. They experienced an increase in the severity of pain during breathlessness. The pain was found to have affected their activities of daily living and caused them to stay at home most of the time. However, patients in [17] study of the lived experience of end-stage COPD experienced only chest pain. Furthermore, previous research presented little findings on other physical symptoms experienced by patients with COPD such as cough [1]. Anorexia, weight loss, sleep disturbance [17] Seamark 2004), frequent chest infection, lethargy and tiredness (Gysels & Higginson 2011; Gullick & Stainton 2008).

Psychological symptoms

The experience of living with COPD concerns not just physical symptoms but also psychological symptoms and the evidence from qualitative research indicates that physical and psychological symptoms are inextricably linked. Psychological symptoms described in previous research on individuals' experiences of living with COPD include fear, sadness, irritability, anxiety and depression [1]; Gullick & Stainton 2008; [17]; Robinson 2005), frustration, anger (Banett 2005), distress and panic (Gysels & Higginson 2010; [25]. In Gysels and Higginson (2008) and [2] studies,

patients described their panic and anxiety as symptoms that were hard to control and led them to collapse sometimes. Similarly, [17] study of exploring the potential for palliative care among 13 patients with advanced COPD found that depression and anxiety were the main psychological symptoms found. Patients in this study expressed worrying about the future because of their unpredictable illness. The stigma of being breathless and suffering due to worsening breathing (Gysels & Higginson 2008, 2011) has also been highlighted. Worsening breathlessness was linked to death as patients with COPD felt that their extreme breathlessness made them feel like choking or suffocating [2] The fear of dying alone was also expressed during the exacerbation of breathlessness [9, 10].

Prevalence of Symptoms

The prevalence of COPD has been studied in epidemiological studies in the past, focusing mainly on mortality, morbidity, and risk factors such as age and smoking. In contrast, there has been a gap in epidemiological studies in prevalence of physical and psychological symptoms in large populations with COPD. However, the prevalence of physical and psychological symptoms among patients with COPD has been studied in a number of small studies. Here, the purpose is to present an overview of the types of symptoms that patients with COPD experience, as well as the number of symptoms experienced at individual level and as a percentage of patient samples across studies [6, 7].

In a cross sectional study, [4] examined the prevalence of symptoms in patients with moderate to very severe COPD (n=100) waiting to begin a pulmonary rehabilitation programme. Patients were older than 35 years, and their FEV1 was less than 80%. The self-report questionnaire of the breathing problem questionnaire [8] Hyland was used to assess symptoms. This instrument includes 10 items to assess symptoms and day to day activities. [4] Used five of the items to assess breathlessness, fatigue, sleeplessness, anxiety, and depression.

This instrument was reported as valid and reliable with reference to previous COPD studies. Pain was assessed by asking patients to respond to a question about whether they generally had pain, and rate it from 1 to 10 using the numeric rating scale. Descriptive statistics revealed that breathlessness was reported by all patients, followed by fatigue (72%), depression (69%), anxiety (64%),

pain (45%), and sleeplessness (28%). In relation to the number of symptoms, 12% of patients reported one symptom, while 16% and 15% reported two and three symptoms respectively. More than half of the patients (46%) reported four symptoms, 23% reported five symptoms, and 11% reported six symptoms. The prevalence of symptoms in this study were consistent with those reported by other researchers with similar or smaller sample sizes [5, 26, 3], Jablonski 2007, Eckerblad 2014). In these studies (Table 1), the Memorial Symptom Assessment Scale (MSAS) was used to assess the

prevalence and symptom burden in patients with COPD. The MSAS includes 26 physical and 6 psychological symptoms [5, 27]. Breathlessness was the most prevalent physical symptom reported by patients with COPD. Other physical symptoms with highest prevalence were lack of energy, dry mouth, cough, numbness in hand and feet, drowsiness, and pain. Worrying, difficulty sleeping, sadness, irritability, and nervousness were the most prevalent psychological symptoms. A median ranged from 7 to 12 symptoms among individual patients were found across these studies [11-15].

Table 1: Prevalence of symptoms in COPD

Study	Breathlessness	Lack of energy	Dry mouth	Cough	Pain	Drowsiness	Numbness	Nervousness	Sadness	Irritability	Lack of sleep	Worrying
[14] N=72	94% n=68	81% n=58	65% n=47	64% n=46	47% n=34	53% n=38	36% n=26	56% n=40	54% n=39	53% n=38	47% n=34	50% n=36
[5] N=100	94%	71%	60%	56%	41%	47%	28%	40%	39%	42%	35%	51%
[3] N=60	86%	84%	65%	78%	69%	87%	37%	48%	57%	47%	69%	65%
	n=42	n=41	n=32	n=38	n=34	n=43	n=18	n=23	n=28	n=23	n=34	n=32
[26] N=86	77% n=67	43% n=37	46% n=40	52% n=45	37% n=32	57% n=49	58% n=50	37% n=32	31 n=27	24% n=21	40% n=35	40% n=35
[8] N=91	90% n=82	55% n=50	65% n=59	65% n=59	44% n=40	N/R	33% n=30	N/R	22% n=20	27% n=25	52% n=47	33% n=30

*N/R: not reported

The Edmonton Symptom Assessment Scale (ESAS) has been used in studies that examined the severity of symptoms in addition to prevalence [29, 30]. The ESAS Bruera 1991 is designed to assess 7 physical symptoms and 2 psychological symptoms in seriously ill patients including chronic illnesses and cancer. Shortness of breath, physical discomfort, fatigue, problem with appetite, and pain were the most prevalent physical symptoms in [31-33] studies. The most prevalent physical symptoms reported in both studies were disease specific symptoms such as breathlessness and fatigue. Anxiety and depression were also reported by patients with COPD [28].

Consequences of symptoms

Physical and functional disabilities were the negative consequences for patients with COPD mostly described in previous research. They complained of being restricted at home, which made

them socially isolated, losing their jobs and facing financial problems (Gysels & Higginson 2011; [1, 3, 6]). Elfoson's (2004) phenomenological study involved six elderly patients with COPD who described how their breathlessness and fatigue affected their independence. They were dependent on home help, families or staff in the nursing homes. Similarly, in other studies, patients with COPD expressed their difficulties of being dependent on others and as a result not being able to fulfil their roles [1, 17, 2] In Barnett's study, patients highlighted the perception of physical ineffectiveness. They complained of having difficulties in washing and getting dressed due to symptoms and some patients considered themselves as housebound.

Severe COPD saw people coming to terms with their diminishing ability to care for themselves. Difficulties with shopping or driving in patients with COPD were examples of losses to their independence.

As their illness progressed, patients with COPD found the basic tasks such as showering and dressing difficult tasks and making them feel useless and dependent on others [1, 2]. Some patients did not consider their limitations as abnormal and did not realise that it is possible to improve their situation [16]. However, some patients experienced happy times and a sense of meaningfulness (EK & Ternstedt 2008).

RESULTS

Previous research shows that patients with COPD experience problematic symptoms in their day-to-day lives that negatively impact on their well-being and functional abilities. Breathlessness was the physical symptom most explored in previous qualitative research, with fewer studies exploring other symptoms associated with COPD such as cough, pain and fatigue. Psychological symptoms described in previous research include fear, sadness, irritability, anxiety, depression, frustration, and anger. The findings suggest that physical and

psychological symptoms may be a burden to patients with COPD [18-21].

It is evident from studies reviewed that patients with COPD can experience a wide range of symptoms. A consistent finding across the above studies is that the highest prevalence of symptoms in patients with COPD relates to symptoms typically associated with this condition such as shortness of breath, cough, dizziness, and lack of energy. Furthermore, the studies indicate that individual patients with COPD typically experience multiple symptoms which can be up to 10 symptoms [22-25].

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