

Stigma towards Patients with Chronic Obstructive Pulmonary Disease: To Help or To Judge?

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Abstract

Chronic Obstructive Pulmonary Disease (COPD), the third leading cause of mortality worldwide, is a highly incapacitating irrevocable health problem, with pulmonary and extra-pulmonary manifestations. According to Suzanne Hurd and Claude Lenfant, it is “the only chronic disease for which the finger of blame can be pointed to a single risk factor – tobacco smoking”. However, only 15-20% of smokers are afflicted. Whereas smoking is far from being the only cause, substantial proportion of COPD cases cannot be explained by smoking alone. The visibility of distressing and frightening physical manifestations of symptoms leads to serious “observable” consequences, such as disability or lack of control, public use of oxygen and rescue inhalers. As a result “they are disqualified from full social acceptance”. However, the stigma is not the only factor responsible for the miseries of those with COPD. In fact, there are many misconceptions in this scenario which have been discussed. The need of a huge awareness campaign for the public to improve their understanding of lung diseases (notably COPD) has been highlighted. The patient, healthcare professionals and the health services should be prepared to play their new role in the management of a chronic disease like COPD “requiring “ongoing management over a period of years or decades”. The importance of a self-management strategy has been emphasised.

Key Words: chronic obstructive lung disease; social discrimination; stigma; self- management; patient engagement; empowerment

Introduction

“If a lung disease takes someone’s breath away, he or she should be given the same treatment – both socially and medically – as anyone else dealing with any kind of disease. Sadly, stigma plays a significant part in the physical and mental well-being of Canadians with lung disease”.

Terry Dean—President and CEO-Canadian Lung Association [1].

Chronic Obstructive Pulmonary Disease (COPD), the third leading cause of mortality worldwide is a complex, multifaceted, highly incapacitating irrevocable health problem, with pulmonary and extra-pulmonary manifestations. It is usually associated with significant concomitant chronic diseases and is an important public health challenge, throughout the world.

In the recent past, numerous reports, from different spots on the globe, have been published regarding stigmatisation of patients with COPD, by general public and healthcare providers. This is based on their impression that “it is a self-inflicted disease caused by smoking and the sufferers deserve no sympathy”. Canadian Lung Association [1] and British Lung

Foundation [2] have expressed their concern and have urged to stop this prejudice. The seriousness of the issue necessitates that it should be discussed in detail.

What is Stigma? And its triggers? And impact?

“Lung disease is not a sentence that people should serve in a prison of isolation. And imposed solitude is just one of the results of stigma”.

Terry Dean —President and CEO Canadian Lung Association [1].

Stigma, a mark of disgrace associated with a particular situation, attribute or individual, has a long and venerable history. In ancient cultures, both Greek and Roman, the word stigma described tattoos and burn marks inflicted into the flesh of criminals and slaves. In medieval Europe, clipped ears were also added to these marks. By the 18th century, stigma extended to signs of disease or physical degeneration.

Erving Goffman, Canadian sociologist, states that stigma is “an attribute that is deeply discrediting” that reduces someone “from a whole and usual person to a tainted, discounted one”. The stigmatized, perceived as having a “spoiled identity”, is disqualified from full social acceptance”. [3].

Dudley describes stigma as “stereotypes or negative views attributed to a person or groups of people when their characteristics or behaviors are viewed as different from or inferior to societal norms” [4].

(a) Inciting Factors

—Visibility of physical manifestations of symptoms that lead to serious “observable” consequences, such as disability or lack of control, public use of oxygen and rescue inhaler. [5]

— The current tobacco control campaigns seem to have a stigmatising effect on the smoker, not only the act of smoking [6].

—In a population-based study using a sample of current and former smokers in New York City, aimed at investigating the determinants of stigma, it was found that apprehension about the health outcomes of smoking, discriminatory attitude towards the smokers and former smokers and social norms and practices were related to smoker-related stigma [7].

(b) Attitude of the On-lookers

A survey was conducted in 2018, by the Canadian Lung Association, to investigate the depth and extent of stigma surrounding lung diseases in Canada [1]. The key findings were as following:

- 29% of the respondents admitted that they felt uncomfortable on seeing someone with an oxygen tank.
- 11% of the respondents said those who smoke deserve COPD.
- 7% believed that all lung diseases were self-inflicted.
- 6% believed that all lung diseases were contagious.

In a US survey of those with COPD, some of them told that they were viewed with disdain: like a leper, almost, as opposed to any other illness that could be thought of [5].

(c)- Social isolation

Psychological stress, anger and negative emotions have been associated with reduced lung function and other adverse respiratory outcomes [8]. Data from the English Longitudinal Study of Aging observed that negative exchanges with family and friends were associated with greater occurrence of depression [9], which could lead to isolation.

(d) Self-conscious emotions:

They are also called self-evaluation emotions and are generated when events reflect on the worth or value of the self in one’s own or others’ eyes. They include shame, pride, guilt, and embarrassment [10].

The Stigma Report 2018, by the Canadian Lung Association, revealed that 39% of patients were experiencing social isolation due to the stigma surrounding their disease. Moreover, 30% of the patients reported that they felt guilty or ashamed of having COPD [1].

A Norwegian longitudinal and descriptive study was designed to investigate how patients with COPD experience daily life in a society with heavy emphasis on tobacco control. The participants were found to have the feelings of disgrace, negative emotions and daily threats to self-esteem and of being “exiled in the world of healthy” because of self-blame and society’s stigmatisation of COPD as a self-inflicted disease [6].

(e) Problems with access to healthcare

Gysels et al have justifiably argued that the problems with access to care are an additional dimension of suffering added to the illness experience [11]. Due to inadequacy of the disease-specific professional competency and sub-optimal training for managing a complex malady like COPD, the healthcare professionals, in most of the cases, fail to understand the

individual requirements of the patients. Moreover, their pre-conceived notion “COPD is a self-inflicted disease” becomes embarrassing to the patients. In a US study, by Berger et al, the patients were found apprehensive because of being ridiculed or chastised by health care providers, specifically on the topic of smoking [5]. This potentially devastating attitude results in feelings of shame and guilt amongst the patients [12]. Lindqvist et al, narrating their observations, in a series of interviewed patients, expressed resentment that those with COPD were not always met with understanding and sympathy; rather negative attitudes could be uncovered, which were particularly noticeable if they had not managed to stop smoking: ‘That thing about smoking, then you don’t get access to care’ [13]. Such a frame of mind adversely affects their future contact with healthcare system to seek care.

While focussing on the issue of medication adherence in COPD, Bourbeau and Bartlett [14] argued that it is multifactorial and that the patients, physicians and society affect it. Rogliani et al added that the interplay between patients and physicians is definitely crucial, while the role of the society is an element that often authoritatively affects this interplay [15]. The patients, burdened by the severity of disease, unprofessional handling by the healthcare providers and stigma from the society blame themselves and the disease. Some of them discontinue their specific medications just to show that they are no longer “associated with stigma-generating COPD”.

The Other Side of the Coin?

The concerns of the Canadian Lung Association, British Lung Foundation and the international researchers, regarding stigma towards the patients with COPD, are not totally unfounded. However, the stigma is not the only factor responsible for the miseries of those with COPD. In fact, there are many misconceptions in this scenario. A brief account would make the picture clear.

1- It is not true that tobacco smoking is the only cause of COPD.

In 2005, Suzanne Hurd and Claude Lenfant had commented “COPD is the only chronic disease for which the finger of blame can be pointed to a single risk factor – tobacco smoking” [16]. While it is true that tobacco smoking is the major risk factor for COPD, it is also true that COPD in never-smokers forms a substantial burden in the population [17]. Both the public health message from the British Lung Foundation [2] and “An official American Thoracic Society Public Policy Statement: Novel Risk Factors and the Global Burden of COPD” [18] make it clear that the smoking is far from being the only cause.

Centers for Disease Control and Prevention (CDC) analyzed state-specific Behavioral Risk Factor Surveillance System (BRFSS) data -2017 indicated that the prevalence of COPD was 15.2% among current cigarette smokers and 7.6% among former smokers [19]. Moreover, as stated in The Rotterdam Study, approximately 20 % of smokers develop COPD. [20.]

The percentage of people, diagnosed with COPD, amongst the never-smokers has been found to be 20% and 25% in the estimates of British Lung Foundation [2] and that of CDC [21] respectively. The analysis of data in the initial cross-sectional phase of the population-based, prospective, multisite CanCOLD Study revealed that the prevalence in non-smokers was 27% of all COPD subjects [17].

2- It is not true that COPD is a “self-inflicted disease”.

Prof. Mike Morgan, National Clinical Director for Respiratory Services in England, argues: “Many people view COPD as a self-inflicted, untreatable, progressive condition that will pass in to history as smoking rates decline. In fact, this is far from the truth as we learn more about this complex condition” [22].

3-The current tobacco control campaigns are not to have a stigmatising effect on those with COPD.

Their vision is “to create a tobacco-free society”, the mission is “to promote individual, community and government responsibility to prevent and reduce tobacco use through multi-sectoral participation in tobacco control” and the goal is “to reduce mortality and morbidity due to the use of tobacco” [23]. They are not there to target the patients with COPD.

4- Stigma is not the main cause of social isolation.

It is well known that dyspnea, fatigue and cough, the main symptoms in patients with COPD, seriously impact on their activities of daily living with resultant psychological distress and social isolation [24]. In a retrospective survey of the informants of 399 deaths from COPD in four London health authorities between January and May 2001, it was found 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. [25].

In an exploratory study, conducted at University of Southampton, into “what really matters to people living with COPD” it was found that people with COPD often experience physical restrictions, which can lead to reduced community mobility and social isolation [26].

5- Stigma is not the sole cause of poor access to healthcare

Qualitative analysis of the disease experience of Korean patients revealed that limited accessibility to health care may be a barrier to obtaining good care [27]. In the context that many rural elders experience limited access to health care, a study was conducted in 6 rural West Virginia communities. The five categories of barriers, emerging from discussions were transportation difficulties, limited health care supply, lack of quality health care, social isolation, and financial constraints [28]. In a Swedish study, “availability”, “continuity” and “professional competency” were the repeatedly uttered words, by the participants, to express their level of satisfaction towards healthcare system. [29].

6- Stigma is not the sole cause of poor medication adherence in COPD.

In an Italian study, it was found that “the medication adherence in COPD is multifactorial and is affected by patients (health beliefs, cognitive abilities, self-efficacy, comorbidities, psychological profile, conscientiousness), physicians (method of administration, dosing regimen, polypharmacy, side effects), and society (patient-prescriber relationship, social support, access to medication, device training, follow-up)” [15]. Caregivers, especially spouses, may improve adherence in COPD. It was shown in The Lung Health Study that married COPD patients were more likely to be adherent to medications than non-married patients. [30]. Moreover, the adherence was higher in the “spousal caregiver” group, as compared to “non-spousal caregiver group” [31].

7- Stigma is not the sole cause of anxiety and depression in COPD.

Anxiety disorders, especially generalized anxiety disorder and panic disorder, occur at a higher rate in patients with COPD compared with the general population. Anxiety has a significant and negative impact on quality of life [32]. In various epidemiological and clinical studies, the prevalence of depression in patients with COPD varies from 7% to 79%, depending on the progression of the disease [33]. In a US retrospective cohort on COPD patients of 40 years and above, it was found that COPD patients with comorbid depression were 48% more likely to have an emergency room visit and 77% more likely to have a COPD-related hospitalization compared with COPD patients without comorbid depression. [34]

Conclusion

“Nature caused us all to be born equal; if fate is pleased to disturb this plan of the general law, it is our responsibility to correct its caprice, and to repair by our attention the usurpations of the stronger”.

—Maurice Blanchot (1907-2003)—French Literary Theorist

Alison Cook, Director of External Affairs at the Asthma UK and British Lung Foundation Partnership, and Terry Dean, President and CEO Canadian Lung Association, have highlighted the need of a huge awareness campaign for the public to improve their understanding of lung diseases (notably COPD). However, only this much is not sufficient. The patient, healthcare professionals and the health services should be prepared to play their new role in the management of a life-long disease like COPD.

COPD is a chronic condition. Whereas the WHO defines chronic diseases as requiring “ongoing management over a period of years or decades” [35], Holman and Lorig [36] suggest a patient-healthcare provider partnership as a key in their management. This is a team approach, with protocol of shared decisions, aimed at providing meaningful and high quality lifelong contact within the existing healthcare system. How to proceed with this partnership agenda?

As a part of a wider UK program “Improving Breathlessness”, a study was conducted which had a qualitative design based on Grounded Theory. The results showed that the low access to services by COPD patients is due to the nature of breathlessness itself, and the way the symptom is addressed by institutions, such as health care services, which discredit the patient's experience [11]. To enhance utility of the existing health system, we need to organize a high quality healthcare team, adequately trained in understanding the depth of the problem and the required management protocol.

The technical head should be the physician with COPD nurse and respiratory physiotherapist as associates. In the present setup the “Lifestyle Medicine Physician” comes close to WHO's Five Star Doctor (Care Provider, Decision Maker, Communicator, Community Leader and Manager). Additionally, when equipped with the tools of motivational competency and a well-defined health-behavior change skill, he is able to introduce meaningful, measurable and attainable lifestyle interventions which are acceptable, doable and enjoyable for the target group. [37]. In self-management conceptualization, the patient is responsible for his own care, with Empowerment, a process meant to enable patient to gain control over his health. The physician, on the other hand, would be taking the responsibility of a mentor, technical adviser and a professional guide. His role is a strong determinant of the level of “Patient Engagement” which is defined as “actions individuals must take to obtain the greatest benefit from the health care services available to them” [38]. The fitting closing sentence would be inspiring and instructive message from Terry Dean: “No matter how or who gets lung disease, everyone deserves positive outcomes..... We are there to help, not to judge”.

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Conflicts of interest

The authors have no conflicts of interest to disclose.

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