

To live a life with COPD – the consequences of symptom burden

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Background: Chronic obstructive pulmonary disease (COPD) is a prevalent illness that, due to its symptoms and treatment, entails a significant burden for the affected person, and his/her family, health care and private finances. Today, knowledge and understanding are sparse regarding COPD-affected persons' own lived experiences and about the symptom burden and its effect on their daily life. Due to this knowledge gap the aim of this study was to identify and describe the symptom burden and its effect on daily life in people with COPD, based on their own lived experiences.

Subject and method: Eleven males and 14 females in GOLD stages III and IV, in an age range of 58–82 years, were interviewed. An interview guide was used to direct the face-to-face interviews. Data was analyzed with thematic analysis following the six steps according to Braun and Clarke.

Results: The results highlighted one theme: an altered everyday life. The altered everyday life leads to a need for support to handle everyday life and for different strategies to live as desired. Persons with COPD need to take each day as it comes and their life is not easy to plan since it depends on how they feel from day to day. Life is handled with several strategies such as breathing techniques, and ways to take care of the home and garden as well as the emotions. Support from the next of kin, society and the health care service is important.

Conclusion: This study provides the insight that persons with COPD in stages III and IV have an altered life caused by the symptom burden. They must struggle with strategies to handle everyday life. There is a need of support from the next of kin and society to facilitate daily living, but this support needs to be well-balanced.

Keywords: chronic obstructive pulmonary disease, symptom burden, daily life, thematic analysis

Introduction

Chronic obstructive pulmonary disease (COPD) is a prevalent disease. In 2030, COPD is expected to be the third most common cause of death in the world.¹ COPD, due to its symptoms such as shortness of breath, cough, and increased mucus production, its exacerbations,¹ and treatment,² such as stopping smoking and pharmacological treatment,¹ imposes a significant burden on the affected person; a burden in terms of reduced quality of life and effects on daily activities. It can lead to reduced physical activity, impaired sleep and increased anxiety and depression, all of which result in a symptom burden.² A connection can be seen between the seriousness of symptoms in the morning, the physical activity and the severity of dyspnea during the day.³ Breathlessness impacts the daily life⁴ in practical, medical and psychosocial ways.⁵ The way to live with COPD is to hide it and battle with the disease.⁶ A quarter of all people who live with COPD also report a burden due to impact on health, family and private finances.⁷ Today, we know more about the effects of shortness of breath

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but the knowledge and understanding are sparse regarding COPD-affected persons' own lived experiences in relation to all the symptoms and their whole daily life. Due to this knowledge gap the aim of this study was to identify and describe the symptom burden and its effect on daily life in people with COPD, based on their own lived experiences.

Method

Study design, participants and setting

A qualitative interview study using an interview guide and data analyzed with thematic analysis by Braun et al⁸ was performed.

This interview study is a part of a larger study, and the inclusion criteria were COPD in GOLD stages III and IV diagnosed by a doctor on spirometry and symptoms, and the exclusion criterion was ongoing exacerbation. For this study a purposive sampling technique was used, which in this study means persons how want to participate and to reach a variation of gender, age and stage in COPD. The participants were recruited between March 2015 and June 2016 at the specialist lung or COPD reception at three hospitals in the southeast of Sweden. When the persons with COPD visited the reception, they were verbally informed about the study and received a prepared take-home package including: an information letter, an informed consent form, the questionnaires for the larger study, a request to participate in the interview and prepaid envelopes. The participants considered the request and returned the informed consent to the first author (HJ), who contacted the participants by telephone, at which time interviews were scheduled at a time and place suitable for them. Persons were included one by one when they had sent in the signed informed consent regarding this part of the study. The study complied with ethical principles for medical research as described in the Declaration of Helsinki.⁹ The persons involved provided informed consent and the study was approved by the Regional Ethical Review Board in Sweden Dnr 2014/394-31.

Data collection

Individual face-to-face interviews were performed directed by an interview guide, and focusing on the daily life affected by COPD. Each interview was carried out during a single visit. The starting point for each interview was to ask the person to talk about life with COPD and how it affected daily life. Probing remarks such as "Please tell me more" or "Could you explain?" were used. All interviews were conducted by the first author (HJ). The interviews were held in the persons' home, in a secluded room at the hospital or

in a public location selected by the participant. The interviews were digitally recorded and lasted between 25 and 70 minutes, with a mean length of 42 minutes. The interviews were transcribed verbatim. The quotations were originally in Swedish but were translated into English.

Data analysis

The transcribed data were analyzed with a thematic analysis in accordance with Braun et al⁸ and followed the following six steps: (1) the text from each interview was read and re-read several times to gain familiarity with the data, and (2) an initial coding was performed. (3) The codes were re-read and generated themes that were connected to each other. (4) The themes were checked with the coded extracts and data and used to generate a thematic map. (5) Thereafter, all themes were merged into a comprehensive map representing all interviews.⁸ The initial themes were symptoms that affect daily life and their consequences, emotions, strategies, and support from the environment. The themes were processed, redefined and clarified once more in order to obtain a few distinct themes.⁸ This resulted in one overall theme. (6) The theme was presented as a coherent pattern and was strengthened with quotes.⁸

The analysis was led by the first author (HJ), and discussed and agreed by all co-authors.

Results

Participants

In total, 25 interviewees were included, with 11 males and 14 females, in the age range 58–82 (median 71) years. The characteristics of the participants are presented in Table 1. They had COPD due to tobacco, air pollutants or genetic factors such as alpha 1-antitrypsin deficiency.

Table 1 Characteristics of the interviewed persons with COPD

| | GOLD stage III | N | GOLD stage IV | N |
|--------------------------------|-----------------------|----------|----------------------|----------|
| Participants | Total | 16 | Total | 9 |
| Age | Women | 11 | Women | 3 |
| | Men | 5 | Men | 6 |
| | Year | 58–82 | Year | 65–80 |
| Living | Single | 6 | Single | 5 |
| | Cohabiting | 10 | Cohabiting | 4 |
| | Apartment | 7 | Apartment | 7 |
| | Villa | 9 | Villa | 2 |
| Practical support ^a | Support | 11 | Support | 7 |
| | No support | 5 | No support | 2 |

Note: ^aHelp with basic needs, home and garden.

Abbreviation: COPD, chronic obstructive pulmonary disease.

The characteristics of the interviewed persons were representative for the COPD population.

The analysis of the interviews resulted in the theme: an altered everyday life. The altered everyday life leads to a need for support to handle the everyday life, and strategies for living a desired life. Quotations are supplied with invented names in order to preserve the interviewee's anonymity.

An altered everyday life

Being hit by and living with COPD, the exacerbations and deterioration have an impact on the person's everyday life. The life is a compromise between life before the disease, will, opportunities, and life with the disease. Life is governed by the influence of the symptoms and how the person feels from day to day. There is a wish to be able to plan the day in advance in order to be able to prepare in practical and mental terms. The day must come and be governed by how the person feels on that day, which is difficult to foresee.

When I get up in the morning and dress, some mornings I can sit for a long, long, long while and then I think, this will not be good. [Lasse, 76 years old]

Life consists of learning to live with and adapt to the conditions and opportunities that exist in everyday life. At the beginning of the disease, before diagnosis, the persons with COPD try to find explanations for the symptoms and other causes for the problems they experience. When the disease is a fact, the persons try to find practical solutions to handle everyday activities. If something must be done or planned, it can be an imbalance in symptoms which then has an impact on the coming days by consuming too much energy in advance. It is a challenge to plan the daily activities, so the energy is maintained, distributed, and lasts the whole day.

I have finished planning my life, that's no use, I found out that if you try to plan something, it will not end up as you planned anyway. [Olle, 80 years old]

At home, everyday life is affected since the persons with COPD do not always manage to take care of themselves, the home, the garden and so on in a desirable way. Practical solutions can consist of planning, prioritizing and allocating daily tasks. In order to facilitate and manage everyday life, factors that worsen the symptoms are also avoided. Life is a balance: to cope with today's energy demands energy needs to be conserved to ensure it is sufficient for the whole day's activities. This causes priorities to become necessary and the day must be taken as it comes. This, together with emotions and the willingness to get practical help and emotional

support make them ambivalent, since they want to succeed and do not want to become dependent on the next of kin.

I'm getting frustrated I'm not able to hurry on [...] I need to ask for help but at the same time I don't want to be dependent on others. [Lasse, 76 years old]

The next of kin and society offer support with practical tasks both in the home and garden. Facilitation of everyday life can come from practical solutions provided by the local authority or private help in the form of housing, transport and disabled parking permission. There is a need for more personalized solutions and sometimes there is a lack of support and understanding from the next of kin and surrounding society. Some next of kin are perceived as overprotective because they do not allow the person with COPD to do what is possible. At the same time it is a fact that not all needs are visible, which can create great difficulty for those who are not present all the time.

The persons with COPD want to participate in social activities and socialize with family, and at the same time they have the feeling of being a burden, since they do not have the energy to participate at the same pace as others.

[...] you never leave home [...] you stay at home while the family is out doing something I am at home because I cannot manage. [Stina, 58 years old]

This leads to the choice of staying at home and can result in isolation. Traveling for pleasure and visiting family are also difficult. Changing the means of travel can be difficult and stressful, and even here the choice may be to stay at home. The experience of respiratory distress as a barrier to everyday life is exacerbated by the weather through heat, cold, wind and moisture.

I would like to exercise but then it starts blowing, raining and snowing and then I give it up. [Karin, 59 years old]

Various factors in the environment have an impact on the decision to engage in or abstain from some activities. The risk of exposure to different scents can be such a factor. The treatment related to the disease, and managing the treatment to gain the best possible symptom relief affect the person's everyday life, and lead to the establishment of routines. Having a desire for a curative treatment causes the person to experiment with the pharmacological treatment, which in turn can lead to overuse of the drugs. At the same time, there is a fear about the future, in terms of becoming more dependent and needing oxygen. Alternatively, those who experienced the use of oxygen thought it was a relief and help. Breathing

problems consume more energy, which leads to weight loss and fatigue. Weight loss is hard because it limits the ability to participate in activities and sometimes causes a feeling of shame about being skinny. Knowledge that the disease cannot be cured is both stressful and painful and along with emotions of guilt at being a smoker may affect everyday life. Those who still smoke try hard to quit, as stopping smoking is an important part of the treatment. The balance between the symptom burden and knowledge of the importance of physical exercise is stressful, as the energy and ability available do not match the desire and need.

up the hill [...]. I walk at my own speed and stop and rest and then move on [...]. I want to be physically active // [...] // and my doctor says I need to exercise. [Greta, 83 years old]

To facilitate everyday life, there is a desire among the persons with COPD to talk and to meet others in the same situation so they can share experiences and give each other tips and advice. Another kind of support that society can provide is a contact person in health care where there is need.

Large parts of everyday life are governed and influenced by the emotions associated with breathing problems and lack of energy. It is depressing to be unable to do what one wishes in life; to be unable to do what one has planned and what gives one happiness. Being dependent on help from others and at the same time the feeling of becoming a burden, leads to a feeling of downheartedness. Despite this, several people had found strategies to handle their daily lives, and to live a good life with the symptom burden.

Discussion

The aim of this study was to identify and describe the symptom burden and its effect on daily life in people with COPD based on their own lived experiences. Daily life is dominated by the need to balance the daily activities and to use energy sparingly. There is a need to see opportunities, and the will to manage places high demands on the person with COPD. Adapting to the opportunities in life and taking the day as it comes can be a challenge. In this situation there is a need for support from the next of kin as well as society, but without taking over. The decreased ability to engage in physical activities agrees with the results of Miravittles and Ribera² and that the status of the person with COPD in the morning directly affects the exercise possibilities for the rest of the day.⁷ The fact that life for the persons with COPD is about being able to plan the day, preserving energy, adapting to circumstances, avoiding some activities, etc makes life complex for these persons.

This causes a feeling of being dependent on others, needing their help, and sometimes there is even overprotection from the next of kin. There is still a desire to take care of oneself. Symptoms affect the physical ability, which in turn affects the person emotionally. The symptoms affect the physical ability, which is also what Gruenberger et al¹⁰ concluded. Avoiding activities for managing everyday life can be stressful for both the person with COPD as well as for the people around. The next of kin need to adapt to the affected persons possibility in the life. Some environmental factors and practical conditions can be difficult to avoid for partners, family and friends. But this is also a problem when visiting public areas, due to deteriorative factors that cause breathing problems and affect the emotions. If the person with COPD is experiencing severe breathing problems it may bring more severe symptoms concerning pain, general health, physical and psychological health and decreased social function.⁷ Health care has an important role in finding individualized treatment, so the person does not need to experiment with the medication. Ding et al¹¹ reinforce this by stating that the treatment choice of single or combination therapy is important. Persons with COPD treated with pharmacological monotherapy have a higher symptom burden than persons undergoing combination treatment.⁸ This strengthens the view that person-centered care is preferable. Miravittles and Ribera² concluded that every person's individual symptoms are important and need to be assessed to give the best individual care and medical treatment. To optimize the health care, a personal contact who can be called is requested for the affected person. A person-centered care plan can be a help,¹²⁻¹⁴ and good treatment can reduce mortality.¹⁵

Thematic analysis is an open method with several possibilities⁸ since the method is flexible regarding sample size as well as framework. The strength of this study is the rich data corpus of 25 interviews, which meets the study's aim. During the whole analysis process there were discussions, and separate analysis was performed by the research group. This way of analyzing strengthens the quality due to researcher triangulation.¹⁶ The challenge was to treat every single interview as a unique unit, and then add it to the data corpus without looking for recognition. A variation of gender, age and GOLD stage III and IV was sought to represent the population affected by COPD.

Conclusion

This study provides the insight that persons with COPD in stages III and IV have an altered life caused by the symptom burden. They must struggle with strategies to handle

everyday life. There is a need for support from the next of kin and society to facilitate life, but this support needs to be well-balanced.

Disclosure

The authors report no conflicts of interest in this work.

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