

## ORIGINAL ARTICLE

# Need of support in people with chronic obstructive pulmonary disease

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**Aim and objective:** The aim of this study was to describe peoples' experiences and expectations of support when living with chronic obstructive pulmonary disease.

**Method:** We conducted and analysed face-to-face or telephone interviews with 17 individuals (aged 44–77 years) diagnosed with chronic obstructive pulmonary disease. The interviewer asked open-ended questions aimed at encouraging further narration, and we analysed the participants' narratives using a phenomenological hermeneutical approach. This report adheres to the COREQ guidelines.

**Results:** The overall theme suggests that people with chronic obstructive pulmonary disease describe support as shared knowledge and experiences, based on the following subthemes; similar experiences, the need of genuine professional knowledge, self-reliance versus self-blame, and the Internet – feeling safe but uncertain.

**Conclusions:** People with chronic obstructive pulmonary disease find their strength through shared knowledge and dialogical support with others who have similar experiences and with professionals. A person-centred eHealth approach may be suitable for this group as it offers both collaboration and support.

**Relevance to clinical practice:** There is a demand for access to genuine professional knowledge as additional support to patients' own capabilities and needs. Patient associations were assessed as reliable sources of information and to some extent also support, but the importance of access to professional sources was also stressed.

## KEYWORDS

chronic illness, chronic obstructive pulmonary disease, clinical nursing, nursing education, support

## 1 | BACKGROUND

The World Health Organization (WHO) estimates that 65 million people around the world suffer from mild to severe chronic obstructive pulmonary disease (COPD) (Vestbo et al., 2013). The prevalence of COPD has increased in recent decades, and it is estimated that by 2020, it will be the third leading cause of death worldwide in the adult population (Mathers & Loncar, 2006).

COPD is a long-term condition, with high rehospitalisation rates and severe impacts on life expectancy and activities of daily living, leading to high costs. The main risk factor for COPD is smoking. Although pharmacological therapy has improved outcomes markedly over the last 10–15 years, management programmes are needed to optimise care (Hardy et al., 2016). Patients diagnosed with COPD have high rates of dissatisfaction about their treatment plans and the nonproductive interactions they experience

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with the professional healthcare team (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015). These patients also often report low quality of life, with symptoms such as fatigue, shortness of breath and anxiety (Strang, Ekberg-Jansson, & Henoch, 2013).

Chronic obstructive pulmonary disease is often associated with increased healthcare use, particularly in primary care (Ahnfeldt-Mollerup, Lykkegaard, Halling, Olsen, & Kristensen, 2016). In 2015, 3.2 million people died from COPD worldwide, and compared to 1990, there is an increased prevalence of COPD by 44.2% (Soriano et al., 2017). Research shows that people who suffer from COPD are burdened with depression and/or anxiety (Janssen et al., 2010); both anxiety about living with the disease and death anxiety (Strang et al., 2013). Most patients find their own coping strategies to handle these life-threatening feelings and difficult situations. Follow-up through telemedicine has shown good results in supporting patients recently discharged from hospital, when they are considered particularly vulnerable (Moreo, Greene, & Sapir, 2016; Ritchie et al., 2016).

Pulmonary rehabilitation, which includes exercise, education and support to improve well-being, has shown to be the most effective therapeutic strategy to improve symptoms as shortness of breath, health status and exercise tolerance. Self-management interventions with the possibility to communicate with a healthcare professional have been found to not only to improve health status yet also to decrease hospitalisations and visits to the acute care (McCarthy et al., 2015). A randomised controlled trial showed that guided deep breathing has a positive effect on respiratory pattern and breathlessness (Borge et al., 2015).

It is therefore important to study the demands and expectations of potential support for people with COPD to make the interventions easily accessible and functional by starting with meeting the users' needs and including them in the design process (Spinuzzi, 2005).

Research on the kind of support needed by patients diagnosed with COPD is lacking; therefore, the aim of this study was to describe peoples' experiences and expectations of support when living with chronic obstructive pulmonary disease (COPD).

## 2 | METHODS

### 2.1 | Design

We used a qualitative design with a phenomenological hermeneutical approach inspired by Ricoeur's interpretation theory (Ricoeur, 1976) to allow us to understand and decipher the patients' narratives. The lived experience is personal, but its meaning can be conveyed through interpreting narratives of the experiences as texts. The method is widely used (Ekman & Skott, 2005; Fors, Dudas, & Ekman, 2014) and includes interpreting the meaning of a text in a structural and comprehensive way. This report also adheres to the COREQ guidelines.

### 2.2 | Participants and procedure

Participants were recruited via advertisements placed in a closed Facebook group for people with COPD, through leaflets, and by a

### What does this paper contribute to the wider global clinical community?

- The participants in this study experienced loneliness and unreliable support.
- Our participants mostly rely on their own resources when managing daily obstacles.
- Strength was gained through shared knowledge and dialogical support with others.
- Genuine professional knowledge was needed along with patients own capabilities.

specialised registered nurse (RN), in the local hospital. Interested participants contacted the researcher via email, message through Facebook, telephone or the RN at the hospital. Those who agreed to participate received a written information letter, and a date and time for the interview was set via mail, Facebook or telephone. The participants could decide if they wanted to be interviewed face-to-face or by telephone. Their choices resulted in three face-to-face interviews and 14 telephone interviews. The inclusion criteria were being >35 years old, having a diagnosis of COPD and being able to understand and communicate in Swedish. The interviewed sample included 17 participants (10 women and seven men) aged 44–77 years old (Table 1). All who were diagnosed with COPD and contacted the researchers were interviewed, and no one was excluded.

### 2.3 | Ethical considerations

Approval for the study was obtained from the Regional Ethical Review Board in Gothenburg (Dnr 687-14). The participants were given written information about the project and the aim of the study and gave their informed consent to participate. The authors were aware that the participants might be emotionally affected by sharing their thoughts and experiences and were prepared to direct anyone who felt disturbed by the research process to suitable support services. All ethical decisions were guided by the World Medical Association Declaration of Helsinki (World Medical Association, 2004).

**TABLE 1** Demographic information of participants

Participants	<i>n</i> = 17
Female	10
Male	7
Age	
40–49	1
50–59	4
60–69	6
70–80	6
Civil status	
Living with partner	6
Living alone	11

## 2.4 | Data collection

The interviewer asked open-ended questions to encourage narration. The opening question was, "Can you please tell me about how you manage your daily life when living with COPD?" The participants were asked some follow-up questions such as what their present situation was like, how they and their family had been affected when they became ill, what type of support they have at present and how they imagined their future if they could decide what type of support to have. The face-to face ( $n = 3$ ) interviews lasted for approximately 1½ to 2 hr and the telephone interviews ( $n = 14$ ) 20–55 min. All interviews were conducted by the first author (LA). The interviews were tape-recorded and transcribed verbatim. The face-to-face interviews were conducted in the participants' homes or at the university.

## 3 | INTERPRETATION AND FINDINGS

The interpretation consisted of three interrelated phases: naïve reading, structural analysis and comprehensive understanding or interpretation of the whole (Lindseth & Norberg, 2004). First, we read the narratives several times to obtain a first impression and overall picture of their contents. This naïve reading indicated that participants needed and valued both an inner dialogue with oneself and a dialogue with others. The structural analysis confirmed the first impressions of the naïve reading and sequences of the text relevant to the aim of the study were identified. These meaning units were excerpted from the text, read individually and critically reflected upon against the naïve understanding. Excerpts with similar content were divided into groups, which were abstracted to form subthemes; subthemes were further abstracted to formulate themes. All authors regularly discussed their pre-understandings from previous care and research of several conditions (e.g., chronic heart failure) during the analysis of data and competing interpretations were considered until agreement was reached. In the final step, the whole text was read again and the interpretation was guided by the naïve reading, the structural analysis and the authors' pre-understandings to formulate an interpretation of the whole.

From the structural analysis, one overall theme was formulated to describe how people with COPD experience daily life and support.

### 3.1 | Support as shared knowledge and experiences

This theme was formulated from four subthemes:

- Similar experiences,
- Self-reliance versus self-blame,
- The Internet—feeling safe but uncertain, and
- The need of genuine professional knowledge.

The subthemes are explained below and illustrated with quotations from the interviews; all citations are labelled with participant (P), to illustrate a representative proportion on contribution from the participants in this study.

### 3.1.1 | Similar experiences

Participants considered it helpful to share their experiences and listen to the experiences of other people living with COPD. The text revealed the importance participants placed on having someone to share their thoughts and worries about their illness with. They greatly appreciated communicating with others diagnosed with COPD because it allowed them to gain important knowledge about how to tackle life obstacles caused by their illness:

*"...We encourage each other very often, send messages. Usually, we know that if you are very weak you cannot talk, so when you send a text message, then you would get in touch that way, and if she hears something, she would tell me and if I would hear anything about COPD or something else I would tell her..."* (P17)

The participants mentioned the Swedish Heart and Lung Association as a particularly good resource for support and frequent updates about COPD as an illness and about treatments. They said that the association offers all new members a personal mentor, usually someone who has been diagnosed with COPD and has a few years of experience living with the illness. Mentors were considered reliable sources of support because they shared knowledge based on their own experience, which participants appreciated more than professional support. Several also mentioned volunteering with different organisations to contribute their experiences of having COPD to help others in similar situations. Having this type of commitment to others motivated the participant to stay strong and to continue to find positive energy to manage obstacles in their daily lives. For some people with COPD, every small activity that normally does not demand much effort can be a struggle.

### 3.1.2 | Self-reliance versus self-blame

The analysis indicated that the informants felt hindered daily by their symptoms. It was difficult for them to walk or to move in almost any way; even talking was sometimes a struggle. They had to find the strength within themselves to keep going:

*"...Yes, particularly this, and it's a nagging concern now as well, though they say that there is not any problem on my behalf, it is nonetheless a nagging concern... just now when I'm out walking, I can like feel, oh, I'm out of breath now. Because I have COPD? Or is it just because I'm in poor condition?..."* (P1)

Having COPD means struggling for a couple of hours in the morning to be able to get the day started and to function in daily activities. Such daily struggles can lead to anxiety and constant worries about not being able to function normally. The informants also mentioned that they did not feel they could share their emotions with others, partly because they did not want to burden their loved

ones, but also because they felt a “you have yourself to blame” attitude from other people including professionals:

*“...Everyone knows and everyone says, I have even heard physiotherapists say, ‘Yes but you smoked and you brought this upon yourself, so you have yourself to blame’. You get it thrown in your face...”* (P4)

Suffering from COPD naturally brings on depressing emotions, anxieties about death and living, and other worries, especially for those who have no one to share their burden. Several participants revealed that they felt depressed because of anxiety, some even to the degree that they isolated themselves at home to avoid public embarrassment due to their symptoms.

### 3.1.3 | The Internet—feeling safe but uncertain

The Internet was a frequently used source for communication at distance. This was an advantage since participants could decide on their own what they wanted to search for. The choice to participate anonymously, for example in a closed group on Facebook, gave participants a sense of safety and comfort. Freely sharing and reading about other people’s experiences was a greatly appreciated source of knowledge and confirmation of their own condition. Access to closed groups on Facebook also allowed them to socialise privately with other group members, some even on a regular daily basis.

Although the web is a large source of information, participants also found books and magazines with necessary information about COPD or other issues of interest. They felt that information published in books and magazines might be more reliable than that published online, because they found the online information to be quite uneven:

*“...the Internet has many users, but unfortunately when it comes to the net, on one site it says one thing, and when you see the next site it says something else. [laughs]...”* (P1)

Not all participants knew how to search for information on the web, or how to find good websites. Several said they found it difficult to understand research and to read articles or other published results online. Even websites belonging to healthcare services were thought to be rather useless and lacking in relevant information for a person living with COPD. Even though most of the participants considered themselves to have good skills in managing technology, they still had difficulty browsing the web for useful and trustworthy information and answers to their questions.

Using the web had benefits for those living far from the closest healthcare facilities. It was convenient to just turn on the computer and search for information or support, or even contact professionals about different matters concerning their health or other health-related issues.

Most appreciated having peer-to-peer support in the Facebook group, although they also mentioned that what is said in the group should be considered carefully, because the information spread in the group might not be reliable. The members of the group post questions about their treatment or their laboratory results and consult other members in those matters, which usually results in several different replies, with none of them certain about the accuracy of the information:

*“...Uh, that one can say about the social media platform that I use, it’s certainly good for many, but I can feel a little that, uh, you throw out a question where you get... uh, ten different answers from... from forty different people...”* (P3)

Most information about COPD online is either shared by professional healthcare organisations or by people who themselves have experience of COPD. The analysis indicates that some of the participants in this study found it difficult to find information that was easy to read online. Even if they did find readable websites, they could not be sure of how reliable the published information was:

*“... you do not know what to look for, there’s no... Sure you can go and read on the healthcare services website but it does not help in practice... And to look for articles that people write is really difficult as well, you never know where to look...”* (P17)

### 3.1.4 | The need to trust professionals

Some preferred going to the specialist team at the hospital to get answers to their questions about their condition, about COPD in general, or about treatment. However, not all participants had that as an option: either they lived in a region in Sweden that did not have a specialist team, or they were not considered to need it after assessment from their physician in primary care.

The participants in this study described a great lack of knowledge about COPD, not only among people in society, but also among professionals. They stressed that there should be more available sources of information about COPD, especially from professionals with great expertise in the subject:

*“...I did get to see a doctor and he, well, he did not really know what he was talking about. He [laughs] really knew nothing about COPD...”* (P13)

The participants recalled several situations when they had gone to the healthcare facilities and either met a physician who did not know much about COPD or had to persistently request laboratory tests that they felt were necessary. They even described degrading encounters with professionals who questioned their illness or even their experience of illness:

*“...There are many doctors who ask, “Are you really sick? Who has given you sick leave?” Because I do not cough, for example. And “Why do you take cortisone” and “Where did you get antibiotics from?” There have been quite humiliating tours due to lacking knowledge in health care, I can tell you...”* (P5)

## 4 | INTERPRETATION AND DISCUSSION

### 4.1 | Support as shared knowledge and experiences

The interpretation of the themes described above, including our pre-understandings and naïve reading, is that people who are diagnosed with COPD describe how strength is gained through support as shared knowledge and experiences.

Congruent with other studies, we also found that patients who are diagnosed with COPD experience barriers in daily life. Some struggles, such as difficulty with physical movements (e.g., walking and for some even speaking), are related to their symptoms. These daily struggles bring up feelings of anxiety, sorrow and for some even symptoms of depression (Chang, Dai, Chien, & Chan, 2016; Pumar et al., 2014). Emotional distress is not always noticeable and can therefore go untreated in people with COPD (Pumar et al., 2014). People diagnosed with COPD have been found to suffer more psychological stress than people with other chronic conditions (Pumar et al., 2014). Healthcare staff, particularly RNs, have a core role in managing health issues in patients with chronic illness but many with anxiety and other mental health issues remain unattended (Hert et al., 2011; WHO, 2007). Participants in this study tended to rely mostly on themselves, which also has been shown in patients with acute coronary syndrome (Fors et al., 2014), to avoid burdening their relatives and closest friends; some even preferred dialogue with strangers who shared similar experiences to going to a professional.

Defining *support as shared knowledge and experiences* may be an attempt to relieve feelings of being stigmatised for a disease considered by many to be self-inflicted. Some participants even isolated themselves at home to avoid the embarrassment of showing their symptoms in public. Stigma, embarrassment and blame from self or others are shaped by the fact that, in Western countries, smoking is a major cause of COPD and negative social representations about it influences others attitudes towards smoking (Berger, Kapella, & Larson, 2011). Participants in a study by (Lindqvist & Hallberg, 2010), like our participants, experienced stigmatising attitudes not only from people in general, but also from healthcare professionals. Participants in our study felt themselves a burden, not only to people in their social networks, but also to health professionals, from whom they felt a “you have yourself to blame” attitude. One way of regaining self-confidence and self-esteem was to talk to others, but also to maintain a strengthening inner dialogue. The strategy of inner dialogue has been shown in other conditions to be a way of coping with and understanding both the symptoms and the diagnosis itself (Fors et al., 2014). Other strengthening strategies were to join

patient associations and to have a mentor linked to the association who has been diagnosed and lived for a few years with COPD. Patient associations were assessed as reliable sources of information and to some extent also support, but the importance of access to genuine professional sources was also stressed.

Being able to communicate and share experiences with others who have similar experiences seemed crucial. In the present study, the Internet was mainly used to search for information, but to some extent also to feel social belonging and support. The Internet's role in helping to confirm and maintain relationships through social media and private groups has also been found in other studies (Ali, Ahlström, Krevers, Sjöström, & Skärsäter, 2013; Foster, 2016; Ventura, Koinberg, Sawatzky, Karlsson, & Öhlén, 2016). The ability to look for information in privacy, when one has the time, and as questions arise also seems important (Helsper & Reisdorf, 2016; Xiao, Sharman, Rao, & Upadhyaya, 2014; Yli-Uotila, Rantanen, & Suominen, 2013). Electronic (eHealth) and mobile (mHealth) technologies are rapidly growing and integrating with today's healthcare services (Findahl, 2011, 2013; Findahl & Davidsson, 2015; Fox & Duggan, 2013). The reason an eHealth support intervention sometimes fails is often that the care is reactive rather than proactive, which means that the users are not involved in the design process and which can lead to patients experiencing less participation in their care (Ali, Krevers, Sjöström, & Skärsäter, 2014; Elf, Skärsäter, & Krevers, 2011; Eysenbach, 2001). However, it has been shown that many factors influence the effect of eHealth support, including the range and quality of the different interventions (Anttila, Välimäki, Hätönen, Luukkaala, & Kaila, 2012; Bender, Katz, Ferris, & Jadad, 2013; Button, Harrington, & Belan, 2014; Camerini, Camerini, & Schulz, 2013). There is a risk that a great flow of misleading information with no available professional to consult to ensure any of its validity may lead to even more uncertainty. Timmins (2005) emphasised the need to provide information to patients about what they need to know in their specific situation; the relational and dialogical aspects of information acquisition are therefore important. COPD is associated with low socio-economic status (Sommer et al., 2015) and it is known that patients with low socio-economic status receive a more directive consultation style and are less involved in care and treatment decisions (Willems, De Maesschalck, Deveugele, Derese, & De Maeseener, 2005). The dialogue between professionals and patients, online or face-to-face must therefore be based on an ethic valuing all people equally. It has been shown that patients who are diagnosed with a chronic illness, especially women, and have low socio-economic status are often associated with increased probability of early retirement (Osler, Mårtensson, Prescott, & Carlsen, 2014). Therefore, professionals need to be receptive and try to identify not only the needs, but also the resources and capabilities, of patients with COPD. Fors, Gyllensten, Swedberg, and Ekman(2016) in a recent randomised controlled trial found that patients with low education significantly improved their general self-efficacy combined with return to work or prior activity levels when they received person-centred care after acute coronary syndrome. Researchers in that study emphasised the partnership and equity between the patient and the health professional, and their agreement on a healthcare plan from the start of the intervention, as crucial to the successful outcome. An approach attuned to each



patient's preferences and needs was also requested of the participants in our study.

*Support as shared knowledge and experiences* can be interpreted as a reaction to traditional consultations in care that are often based on the professional's advice rather than the patient's point of view; hence, most existing eHealth interventions are designed for one-way communication (Gammon, Berntsen, Koricho, Sygna, & Ruland, 2015). To meet today's demands for accessible and efficient care, it is important to develop new methods to facilitate partnership between professionals and patients (Imison, Castle-Clarke, Watson, & Edwards, 2016). The rapid growth in the use of different online platforms stands in contrast to progress in evaluations of their use in healthcare services, especially for people with chronic illnesses. Therefore, it is important to engage users in the design process and aim to combine the human and the technical perspective. The importance of sharing knowledge and having dialogue with others was the main theme found in this study. A person-centred dialogue emphasises the value of listening to individual patients' stories and identifying their resources, which several studies have shown to result in important benefits for both patients and clinicians in general (Ekman et al., 2012; Fors, Taft, Ulin, & Ekman, 2015; Fors, Ekman et al., 2015, 2016; Sjögren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2015).

A person-centred dialogue is based on the agenda of the patient and combines the patient's experiences and resources with the perspective of health professionals to emphasise the role of the patient as a partner in care (Ekman et al., 2011). Person-centred interventions have shown significant effects for several chronic conditions, for example, reduced length of hospital stay and better preserved activities of daily living in patients with chronic heart failure (Ekman et al., 2012) and improved health-related quality of life in palliative care for patients with chronic heart failure (Brännström & Boman, 2014). This care, based on an ethic of mutual respect and awareness of equity, needs to be evaluated also in patients with COPD. Future efforts are warranted to develop and evaluate eHealth solutions allowing person-centred multi-way communication at distance, for example through the Internet.

## 4.2 | Limitations and strength

The current study has several limitations. First, the inclusion criteria were broad since we wanted participants from mild to severe COPD to learn about several different aspects of support that was needed and used by the whole group of people with COPD. Second, the recruitment of participants to the study through Facebook may bias a selection in favour of patients using the Internet on a daily basis. The sample size may also seem to be small, but for a qualitative method 17 participants is a rather large sample and the interviews were rich and sufficient for the analysis to be reliable. Trustworthiness and validity were established by all authors being involved in the analysis, discussing and agreeing on themes and subthemes. In this study, data were collected either by face-to-face or telephone interviews, which could impact both in length and the depth of the conversation. The main authors do not have any experiences from COPD, which might offer an unbiased interview process.

## 5 | CONCLUSION

This study emphasised that patients diagnosed with COPD found their strength through shared knowledge and experiences with others who also have COPD and through maintaining and strengthening an inner dialogue with oneself. The participants tended to rely mostly on themselves in facing difficult daily obstacles caused mostly by their severe symptoms. The information and support found on the Internet was based on their own individual preferences, and provided emotional support, but was not always reliable. There was a demand for access to genuine professional knowledge as additional support to patients' own capabilities and needs.

## 6 | RELEVANCE TO CLINICAL PRACTICE

This study showed that people with COPD experience a lack of knowledge on COPD from healthcare professionals, when having the chance to encounter them at the healthcare facilities. We also found that people with COPD rely mostly on their own resources to gain knowledge about their condition, particularly by sharing their stories with others and searching on the web. However, there is a risk that a flow of misleading information with no available professional to consult, to ensure its validity, may lead to even more uncertainty. This is why the findings in this study are highly relevant to all healthcare professionals in clinical practice.

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## CONTRIBUTIONS

Study design: LA and IE; data analysis and manuscript preparation: LA with critical input from AF and IE; revisions on the drafts: all authors; approval of the final version: all authors.

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