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Enhancing Confidence and Coping with Stigma in an Ambiguous Interaction with Primary Care: A Qualitative Study of People with COPD

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ABSTRACT

Meaningful and high-quality interactions between people with COPD and healthcare professionals are essential to accomplish effective and efficient self-management.

This study's aim was to explore how people with COPD experience COPD-related interactions with healthcare professionals in primary care, and how these interactions influence their self-management and how they cope with their disease.

Interviews were performed with eight women and five men with COPD, and grounded theory guided data collection and analysis.

The analysis resulted in a theoretical model and the core category *(Re)acting in an ambiguous interaction*, representing a dynamic process in which *healthcare priorities*, *healthcare professionals' attitudes* and participants' *personal emotions* were important for the participants' experiences of interactions, and how they managed and coped with their disease.

Mutually respectful and regular relationships with healthcare professionals, along with a personal positive view of life, empowered and facilitated participants to accept and manage their disease. In contrast, experiences of being deprioritized and not taken seriously, along with experiences of fear and stigma, disempowered and inhibited participants in making healthcare contacts or forced them to compensate for experienced insufficiencies in primary care.

In order to facilitate meaningful and high-quality interactions and enhance patient-provider partnerships in primary care, there is a need to improve the status of COPD, as well as to increase competence in COPD management among healthcare professionals and support the empowerment of people with COPD. Findings from this study could guide the implementation of improved self-management support in primary care for COPD and other chronic conditions.

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Empowerment; self-management; healthcare professionals; grounded theory; ambiguity; chronic disease; encounters

Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic condition requiring lifelong contacts within the healthcare system and continuous interactions with healthcare professionals for effective and efficient self-management [1–3]. A COPD self-management intervention should be individualized and support people with COPD to maintain healthy habits, to change their behavior if needed, and to develop skills for managing their disease [2]. Pulmonary rehabilitation, an intervention in which self-management promotion is one of the strategies, is recommended for all people living with COPD [4]. Holman and Lorig [3] suggest a patient-provider partnership as a key in chronic disease self-management, where the patient is the principal caregiver responsible for daily coping with and management of the disease, while the healthcare professional is the professional adviser and teacher. Furthermore, Currie et al. [5] reported that, for people with heart failure (who have symptoms similar to

people with COPD [6–7]), self-management was supported when the patient-provider partnership was characterized by effective listening, respect, and continuity.

Interactions between patients and healthcare professionals in healthcare settings are interpersonal processes vital to the quality of healthcare [8]. In a conceptual framework by Stewart et al. [9] interactions comprises three dimensions: communication, decision-making and interpersonal style. The framework presents characteristics for each of these dimensions that are important for a meaningful and high-quality interaction. In the communication dimension, the importance of explaining and providing information clearly is highlighted, as well as listening and responding to what others say [9]. Empowerment, a process meant to enable patients to gain control over their health [10–11], is also presented as an important aspect of the communication dimension [9]. Empowerment can be seen as a co-creation in the interaction between the patient and healthcare

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professional, where a caring relationship facilitates a personal process that mobilizes the patient's own capacities and resources [10]. The decision-making dimension pertains to the need for patients to be involved in decisions related to treatment [9]. Shared decision-making during healthcare visits has been shown to result in higher patient satisfaction and confidence, and to reduce concerns about illness [12]. Finally, the interpersonal style dimension suggests that respectfulness, friendliness and emotional support are necessary for a meaningful and high-quality interaction [9]. A patient-provider partnership can be seen as a high-quality interaction where patient and provider have equal authority [3]. Pinto et al. [13] found that for trust and agreement, and to strengthen the interaction between patient and healthcare professional, it was important that the healthcare professional was comforting and caring, and showed the patient interest. In the interaction between people with COPD and healthcare professionals, satisfying communication and shared decision-making are associated with perceptions of high-quality care for the chronic condition [14].

However, despite the emphasis on meaningful and high-quality interactions in healthcare settings, studies have shown that improvements are still needed for healthcare visits related to COPD [1]. The degree of shared decision-making, for instance, has been shown to be low, with the healthcare professionals taking the leading role [1]. In our previous study [15], we showed that healthcare professionals perceived that people with COPD had limited influence on their own healthcare because of insufficient knowledge about COPD. Therefore, in order to improve the provision of self-management interventions, it is important to explore how people with COPD themselves experience interactions with professionals in healthcare, and what characterizes these interactions from the patients' perspectives. More knowledge is also needed about how these interactions affect how people with COPD cope with their disease and how this altogether influence their self-management.

Purpose

The aim of this study was to explore how people with COPD experience COPD-related interactions with healthcare professionals in primary care, and how these interactions influence their self-management and how they cope with their disease.

Methods

Study design

This qualitative study was guided by grounded theory (GT) as described by Charmaz [16]. This approach focuses on processes and actions and was found to be appropriate given the aim of this study. GT is an emergent and flexible method with guidelines for collecting and analyzing data, and constructing theories grounded in empirical data. Accordingly, we used theoretical sampling, where participants were recruited gradually, and data collection and data

analysis were performed in a parallel and flexible process. The data analysis guided the recruitment of participants, and the new interviews enabled testing and revision of emerging categories and hypothetical ideas from the analysis. Constant comparisons [16], a characteristic of GT, were used, meaning that we were going back and forth between the data and the analysis. Preliminary analytical notes were written down as memos [16] and were used throughout the analysis process. The principles of theoretical saturation [16] were applied, which means that data was collected until the categories were fixed and that new interviews did not contribute new content or ideas. The study is presented as is recommended by standards for reporting qualitative research (Appendix 1) [17].

Setting

This study was part of a mapping procedure [15] that preceded a larger study with the aim of developing and evaluating an eHealth tool to increase the provision of evidence-based COPD management in primary care [18]. It was carried out in a region in northern Sweden where a large part of the population lives on the coast, while the inland is more sparsely populated. The coastal area has a considerably younger population than the inland area, where every fourth person is more than 65 years old [19]. All citizens in Sweden have the right to enroll in a primary care center of their choice. All primary care centers, both public and private, are publicly funded, as is the case for all healthcare services in Sweden. Most people with COPD in Sweden are treated in primary care, where a gap between provided healthcare and treatment guidelines has been reported [15]. Designated nurses (COPD nurses) coordinate the COPD care for all enrolled patients with COPD and COPD nurses are available at most primary care centers [15]. Four primary care centers in the region were involved in the recruitment of participants. From the coastal area, two urban centers and one rural center were chosen, while one rural center in the inland area was chosen. One center was private and the other three public.

Recruitment and participants

COPD nurses at the centers assisted the researchers with the recruitment of participants. In line with theoretical sampling [16], the emerging and parallel analysis guided the desired variation in the recruitment of participants. Variation among participants was striven for regarding sex, age, urban/rural living, work situation and how they perceived their symptoms. Thirteen people were identified by the COPD nurses, invited by the researchers by telephone and accepted to participate in the study (Table 1) before theoretical saturation [16] was reached. All participants who were contacted by the researchers accepted participation.

The participants described that they were diagnosed with COPD less than one year, and up to 40 years ago. Their perceived symptoms varied from having no symptoms at all to coughing mucus and being a bit breathless during walks, to

Table 1. Characteristics of the participants included in the study.

Participants	
Sex/gender (n), women/men	8/5
Age (years), mean (range)	69 (48-80)
Living area (n), urban/rural	4/9
Work situation (n), retired/working	9/4
Smoking status (n), current/former	6/7
FEV ₁ % predicted, mean (range)	52 (28-91)
FEV ₁ /FVC (%), mean (range)	49 (29-65)

Abbreviations: FEV₁, forced expiratory volume in one second; FVC, forced vital capacity.

a need to abstain from both housekeeping and hobbies due to dyspnea. Apart from COPD, most participants also reported other health issues, from joint problems to cardiovascular problems. All participants were born and raised in Sweden and had more or less regular contact with a COPD nurse at the primary care center, while physicians were only involved when needed. Other healthcare professions were more rarely involved. Contacts with primary care most often concerned medication, assessing symptoms and receiving support for smoking cessation, while other interventions were less frequently received.

Data collection and analysis

In line with the emergent and flexible method of GT [16], the data collection and analysis were performed as a parallel process, in the following described as two sets of data collection and analysis.

A first set of semi-structured interviews were conducted as part of data collection for the larger study [18]. Two researchers (doctoral student SL and postdoc MT) conducted the interviews at primary care centers, in participants' homes or at the university, according to the wishes of the participants. Participants and researchers had no relationships prior to the study and no other persons were present during the interviews. Before interview questions concerning interaction with primary care were raised, background information about time since diagnosis, perceived symptoms and other health issues were collected. Information about pulmonary function was obtained from medical charts. Open-ended questions, following a thematic interview guide (Table 2), were used, such as the opening-question "How do you experience the interaction with primary care regarding your COPD?". The interviews lasted between 20 and 60 min, most being 40-60 min long. Field notes were made by the researchers after the interviews. All interviews were audio-recorded and transcribed verbatim by a professional transcriber. The data analysis was inductive and followed the analytical phases of GT: initial coding, focused coding, axial coding and theoretical coding [16]. During the initial coding [16], the transcripts were read line by line and paragraph by paragraph, and were coded, preferably with codes that contained a verb to illustrate actions. The software OpenCode 4.03 was used for this part of the coding procedure [20]. In the next step of focused coding [16], the initial codes were compared and gathered in smaller clusters based on content to discover patterns throughout the material. Subsequently, during axial coding

Table 2. Thematic interview guide used for data collection.

Thematic interview guide
Experiences of COPD-related interactions in primary care
Support and interventions received in primary care
Support and interventions needed to manage and cope with COPD
Division of responsibility and decision-making in the interaction
The interaction from a diversity perspective

Abbreviations: COPD, Chronic obstructive pulmonary disease.

[16], the smaller clusters were merged into subcategories and categories that were related to each other. Since theoretical saturation [16] was not reached after the analysis of the first set of data collection with six interviews, more interviews were performed in line with theoretical sampling [16].

The second set of data collection with seven interviews was conducted by the first author (SL) at participants' workplaces, homes or primary care centers. The interview guide was slightly modified so as to answer questions that were raised in the emerging analysis. Thus, questions with a clearer focus on the interaction were added, such as division of responsibility and decision-making, with the interviewer asking such questions as "How are you involved in the decisions made about your care?" and "What does the collaboration between you and healthcare professionals look like?". The follow-up questions were, in line with GT [16], modified for each interview in order to further explore and deepen emerging categories and hypothetical ideas from the analysis. The interviews were recorded, transcribed and analyzed in the same manner as the first set of interviews. Finally, a theoretical model [21] was created, discussed and revised to explore and illustrate how the categories and subcategories were related to each other as a result of the theoretical coding [16]. A core category was formulated, representing the characteristics of the experienced interaction and its influence on the participants. During the last interviews no substantial new information could be added to the categories and subcategories, whereby we considered theoretical saturation [16] reached.

To ensure trustworthiness [22], several arrangements were made during the process of data collection and analysis. As part of triangulation [22], and during the entire analysis process, the main responsible researcher (SL) discussed emerging findings with coauthors (MT, MW, KW). All involved researchers thus contributed with different competences and perspectives. To further enrich the analysis, peer-debriefing [22] was used whereby the emerging analysis was presented and discussed at two seminars in the research unit; one seminar with researchers with qualitative research competence and one with doctoral students in physiotherapy with experience from clinical work. Participants were not contacted for comments on transcripts or analysis.

Ethics

All participants received oral and written information concerning the study and gave oral and written informed consent before the interviews were conducted. No specific information about the researchers was provided to the

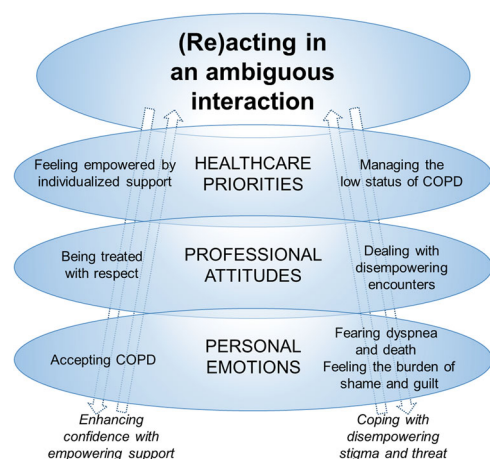


Figure 1. The theoretical model of experiences of interactions in primary care, comprising a core category and three categories with interrelated subcategories pervaded by two contrasting paths.

Abbreviations: COPD, Chronic obstructive pulmonary disease.

participants. The confidentiality of the participants was ensured throughout the entire research process. The study was conducted in accordance to the Helsinki Declaration and gained approval from the Regional Ethical Board, Umeå University, Umeå, Sweden (Dnr 2014-319-31, Dnr 2016-380-32 M).

Results

The analytical procedure resulted in a theoretical model including a core category representing participants' experiences of interactions with healthcare professionals in primary care (Figure 1). In addition to the core category, the model consists of three categories with interrelated subcategories. Two contrasting paths pervade the categories and subcategories, which capture ambiguity in the interaction.

(Re)acting in an ambiguous interaction

The core category *(Re)acting in an ambiguous interaction* represents experiences of a process that was both satisfying and insufficient for the participants. The interaction influenced, and was influenced, by the participants' management and coping with a burdensome disease. The core category comprises the three categories *Healthcare priorities*, *Professional attitudes* and *Personal emotions*. These categories capture aspects of importance for the participants' experiences of the interaction with healthcare professionals at organizational, professional and patient level. All categories consist of contrasting subcategories that refer to ambiguity in the interaction, and how this ambiguity influences how the participants are reacting to their disease and the interaction, and how they are acting in order to actively manage their disease. In the theoretical model (Figure 1), this ambiguity is illustrated as two contrasting paths where the interaction can both facilitate and inhibit the participants' self-management and coping. The path *Enhancing confidence with empowering support* comprises subcategories referring to how a regular, respectful and empowering interaction,

along with a personal positive outlook on life, were perceived as helping the participants to accept their disease and to make choices to improve health. The path *Coping with disempowering stigma and threat*, comprises subcategories referring to how experiences of not being prioritized and being abandoned by primary care, along with emotional burden, could either inhibit the participants' self-management or force them to take responsibility to compensate for shortcomings in primary care.

The interaction between patients and healthcare professionals in primary care is seen as a dynamic process, which in this context means that a participant's experiences may be represented by more than one subcategory and category, and by both paths at the same time.

Below, the categories with interrelated subcategories are presented and illustrated using representative quotes.

Healthcare priorities

The healthcare priorities category refers to ambiguity in the participants' experiences of the healthcare received in primary care, how their disease (COPD) was valued and prioritized in general and at an organizational level, and how this influenced their confidence and management of exacerbations. It consists of the two contrasting subcategories *Feeling empowered by individualized support* versus *Managing the low status of COPD*.

Feeling empowered by individualized support

This subcategory captures experiences of a general satisfaction with trustful COPD-related contacts with healthcare professionals in primary care, where health services and information were adapted to their individual needs.

"Availability" and "continuity" were recurring words that were used when participants described what made them satisfied with healthcare. They felt safe when healthcare professionals were available, both by telephone and face-to-face. The COPD nurses were perceived to have time set aside for people with COPD and greater competence in COPD, which was pointed out, in particular, as being important and reassuring. Having a continuous relationship with a healthcare professional was expressed as crucial:

It gives me a great sense of security, knowing that she's there. And that I won't have to go through that thing where you have to deal with someone new and go through your medical history again; she knows me. She sort of knows my background and my history and she has everything right there in her computer. (Woman, 68 years)

A personal and continuous relationship was also experienced as making it easier to come in contact with the right healthcare professional and get the help that was needed in right time. Regular follow-ups in primary care were experienced as reassuring, were believed to prevent exacerbations, and an aid in regaining an active lifestyle.

Managing the low status of COPD

This subcategory, in contrast, refers to participants perceiving COPD to be a disease with low priority in primary care. The healthcare professionals were perceived to be stressed, and in comparison to other chronic diseases, COPD was rarely mentioned when the participants visited primary care for other reasons. Even though the participants wished for more support and treatment, spirometries and medication were all they received at times in primary care. Questions were raised about whether healthcare professionals had sufficient interest, time, routines and competence for supporting people with COPD. Other considerations that were mentioned included questions about whether the same resources were invested in COPD-related research and additional training of healthcare professionals as for other diseases. The participants also had experiences of varying quality in different primary care centers. Concerns were presented for “less-driven patients”, who, unlike them, did not actively choose their preferred primary care center.

A lack of scheduled follow-ups were perceived as placing the responsibility on the individual to contact primary care when needed. However, despite the healthcare professionals’ instructions, participants experienced not being taken seriously when calling about an exacerbation:

And then I feel like even when you get a little bit worse, you’re still not sufficiently ill to get an emergency appointment and get help right away, but you’re still too sick to wait three weeks for an appointment. So you end up in some kind of limbo that no one understands. (Woman, 48 years)

Instead, they had to wait until the situation became more acute before getting an appointment quickly. Participants also experienced problems in getting the right medication during an exacerbation. Despite such difficulties, they believed that healthcare professionals wanted to help, but that they were unsure and needed more resources and education regarding COPD.

Professional attitudes

The professional attitudes category reflects the ambiguity in the participants’ experiences concerning how they were treated by healthcare professionals in primary care and how these experiences influenced the interaction and their satisfaction and motivation to make decisions about healthcare. It consists of the two contrasting subcategories: *Being treated with respect* versus *Dealing with disempowering encounters*.

Being treated with respect

This subcategory concerns participants’ experiences of positive attitudes among healthcare professionals in primary care. Healthcare professionals were perceived as caring, helping and forthcoming. The participants felt they were encouraged regardless of their sex, age or diagnosis.

Listen, they’re awfully nice when you’re there, hell, you couldn’t ask for better care. (Man, 72 years)

When the healthcare professionals made them feel welcome, participants found it easier to contact primary care when the need arose. Decisions about their healthcare were made in collaboration with COPD nurses and to be involved in decision-making was emphasized as important:

Yes, it has to be something we decide together. With a little more input on my side. It is my body after all. (Man, 77 years)

The importance of being listened to, taken seriously and being treated well was emphasized. Furthermore, the healthcare professionals were perceived to show respect for the decisions they made, and were careful not to impose guilt on them when they were giving information about smoking cessation. Finally, the social aspect of the interaction was also experienced as being important. It was valuable and inspiring to be able to sit down and chat a while, either with healthcare professionals or a group of fellow patients.

Dealing with disempowering encounters

This subcategory, in contrast, represents feelings of being left alone with the disease and that no one in primary care really cares:

It’s up to me to get in touch, and as long as I don’t contact them there’s no one who cares about my disease or me, so to speak. It kind of feels that way. Like you’ve been abandoned. (Woman, 48 years)

The participants felt like they had no one to ask questions to, because of the few follow-ups. Instead, they had to bring up these matters during other visits or had to save these questions for an annual follow-up. Experiences of not being believed and taken seriously in primary care, along with feelings of not being welcome, could make the participants wait unnecessarily long to seek care.

In their encounters with primary care, participants experienced that they sometimes were being “pigeonholed” because of their COPD diagnosis, implying that the healthcare professionals blamed COPD or smoking for all their symptoms. Further, even if advice on smoking cessation was seen as being the healthcare professionals’ task, their nagging about smoking only made the participants “turn a deaf ear to”. Finally, information about taking medications that ran counter to their own experiences with effects and side effects, or unclear information about their diagnosis or treatment, affected their trust and caused skepticism toward their diagnosis or treatment.

Personal emotions

The personal emotions category points to ambiguity in how the participants were coping with their severe and shameful disease and how this way of coping influenced and were influenced by the interaction. The category consists of three contrasting subcategories: *Accepting COPD* versus *Fearing dyspnea and death* and *Feeling the burden of shame and guilt*.

Accepting COPD

This subcategory points to how participants attempted to be positive and live a normal life despite their COPD and how this facilitated their self-management and contacts with healthcare professionals. In order to live life “as usual”, they expressed that it was important to take individual responsibility for improving their health. Hence, they became motivated to interventions such as being vaccinated before visiting their grandchildren to lessen the risk of getting the flu, which made it necessary to contact healthcare professionals. Overall, they did not worry so much and did not spend much time thinking about infections or their COPD. It was perceived as important to have a positive view of life and to be able to laugh. One participant described that she did not let the disease have a negative influence on her life:

No, there's not much that gets me down. That's not my life philosophy (...) Nah, it's not my philosophy to be a sourpuss. (Woman, 69 years)

In addition to an encouraging relationship with healthcare professionals, a social network with supportive friends and family who could help out when needed was perceived as being important in order to keep their spirit up and to make healthy choices.

Fearing dyspnea and death

This subcategory, in contrast, comprises participants' worries related to the severe symptoms and progression of COPD, and a lack of support from primary care on how to deal with this. Healthcare professionals in primary care had not provided sufficient information about how life with COPD could be, and they were afraid that the future wasn't especially bright for them:

Personally I've said many times ... it sounds cynical now ... that I would be grateful if I go quickly, considering my alternatives, with oxygen tanks and this and that going forward, and ... I don't know. Just fading away. (Man, 79 years)

Fear of death became evident when they experienced progressive worsening of their disease, and exacerbations could easily lead to anxiousness. Situations with dyspnea often caused panic and a fear that the end was near:

It's like you get a cramp and then you can't get the air in; you can get it out, but you can't get any new air in. And then the panic hits you. You start to get really scared and then you feel your fingers going numb. (...) I think I'm going to suffocate. I do. I think I'm going to suffocate. (Woman, 48 years)

Even though these anxiety-ridden situations were explained to healthcare professionals in primary care, the participants experienced difficulties obtaining support, which led them to avoid situations and activities where dyspnea and exacerbations could be triggered.

Feeling the burden of shame and guilt

This subcategory encompasses the struggles that participants had with their self-image in encounters with primary care and other social relations. They expressed that COPD “is something you have caused yourself”, a blame that was also

shared by society, especially older generations. The experienced burden of shame and guilt made them hesitate to contact primary care, since they were afraid of “troubling” healthcare professionals. They also expressed concerns of how other patients would react if they were prioritized in primary care:

And then there are always people who sit in the waiting room and think ... “why the hell does he get to go first? What makes him so special?” (Man, 77 years)

Hence, the support from the health professionals was important in overcoming shame and receiving the medication and prioritized visits that were needed. A reluctance to “become” the disease created the consequence that the participants avoided telling others about their COPD diagnosis, which could lead to feelings of loneliness.

Not many of the people around me know that I have COPD. I don't tell them. (...) Up until now, I've just said that I kind of just breathe a bit heavily. (Woman, 68 years)

In encounters with healthcare professionals in primary care, there were experiences of even more shame when participants received support for smoking cessation and still were not able to stop smoking. An urge to avoid talking to supportive healthcare professionals became a consequence, since they felt so much shame. The participants thought it was a pity that COPD is shameful and emphasized that this is something that needs to be changed by talking more about the disease.

Discussion

The main result, as presented in the theoretical model (Figure 1), points to how people with COPD reacted and acted in ambiguous interactions with healthcare professionals in primary care. As illustrated by the two contrasting paths, the participants perceived enhanced confidence from empowering support, but at the same time, they had to cope with disempowering stigma and threat. The prioritization of COPD in primary care, the attitudes of healthcare professionals, and the personal emotions connected to COPD were all aspects that influenced the interaction and how the participants managed and accepted their disease. This interaction among organizations, healthcare professionals, and patients has also been previously reported to affect self-management strategies, both for patients in general and for people with COPD in particular [1, 23].

This is the first study, to our knowledge, that explores how people with COPD experience interactions with healthcare professionals in primary care, and how these interactions influence their self-management and how they cope with their disease. In our study, decision-making [9] was an important aspect in the interaction. Participants preferred shared decision-making in a regular and trustful relationship with healthcare professionals, and their description of this relationship can be compared to the meaning of partnership [3]. In a recent study, Wouters et al. [24] concluded that partnership in healthcare is crucial to be able to offer individualized pulmonary rehabilitation to people with COPD.

In general, shared decision-making [9] is considered crucial for empowering and enhancing confidence and motivation. In addition, shared decision-making has been reported, among people with COPD, to improve health status, adherence to treatment, COPD knowledge and physical activity level [25]. Shared decision-making is supported by Swedish law, where it is stated that healthcare should be designed and performed in consultation with the patient, and that interventions should be based on the individual's wishes and prerequisites [26]. This requires that healthcare professionals respond to their patients' preferences [9].

Despite its demonstrated importance, the amount of shared decision-making has been reported to be low in interactions between people with COPD and healthcare professionals [1]. Healthcare professionals seem to be ambivalent on this dimension: they value people with COPD being involved in decision-making, but at the same time, they want to retain some control and not have patients that are too knowledgeable and too involved [18, 27]. Healthcare professionals who value patients being involved in their own healthcare are more likely to display more collaborative and partnership-building behaviors, and their patients are more likely to be more involved over time [28]. Being involved in decision-making was perceived as a way of being shown respect by the healthcare professional, which was also reported in another study [29].

Overall, the interpersonal style [9] was crucial for our participants' experiences of interactions. In addition to respectfulness, it was important for them that interactions with healthcare professionals were welcoming and caring. At the same time, negative attitudes from society and healthcare professionals, experienced by our participants, could cause feelings of being a burden to others, and that there was no one with whom they could share disease-related worries, findings that also have been reported previously [30–31]. These negative feelings could have a deleterious effect on decision-making.

Notably, the participants in our study were coping with emotions of guilt and shame, which could be barriers to having empowering, high-quality interactions with primary care healthcare professionals. Lazare [32] suggested that diseases can be stigmatized if they are believed to be caused by behaviors that are perceived as "stupid", such as smoking. In the subcategory *feeling the burden of shame and guilt*, our participants blamed themselves for causing COPD by smoking and did not want to "trouble" the healthcare professionals or be prioritized above others. Guilt is a sense of personal failure and may contribute to a will to make restitution to others [32], and this feeling has been confirmed in studies of people with COPD who did not see themselves as worthy of healthcare and wanted others to be prioritized before them [31, 33–35]. Shame is different from guilt, in that shame concerns the whole self, and feeling shame means that one has not lived up to one's own standards. Shame is experienced in social interactions when one sees oneself through the eyes of another person [32, 36], and a common response to shame is to want to hide or disappear [32]. In this study and others [30, 34, 35, 37], people with

COPD avoided telling others about their diagnosis, and tried to hide their symptoms due to the risk of embarrassment. The burdens of guilt and shame therefore influenced help-seeking behavior, self-management strategies, and interactions with primary care professionals. Scheff [36] suggested that the patient-provider partnership can be strengthened if shame is acknowledged, while unacknowledged shame can cause alienation. The importance of acknowledging shame, further shows that a healthcare professional's approach to a patient with COPD is crucial, because a healthcare professional can help a patient to prevent and manage stigma-related emotions.

Additionally, our findings and those of other studies [35, 37, 38] showed that people with COPD might delay seeking healthcare or be less engaged in self-management activities if they perceived that healthcare professionals were too busy for them, or if they expected to be stigmatized. Here, the organization (i.e. the healthcare system in primary care) has an important role, since the perceived low status and priority of COPD in primary care influenced our participants' self-management and coping. Healthcare professionals have been reported to perceive COPD as having low status and priority in primary care, and they felt that COPD is considered less important than other chronic conditions [15]. Hence, it is important to make it obvious to people with COPD that the organization and healthcare professionals prioritize their disease, in order to decrease their perceptions of not being worthy healthcare.

Our results showed that communication [9] between healthcare professionals and people with COPD was important and had an impact on the participants' actions and reactions during the interaction. Empowerment is an important part of communication [9] and the participants in our study asked for more support and information from primary care healthcare professionals. Lack of knowledge in people with COPD has been reported previously [15, 37, 39–42], and Cicutto and Brooks [29] suggested that lack of knowledge is a barrier to people with COPD getting involved in their own healthcare. This might explain why few people with COPD ask questions or offer opinions during consultations and are therefore perceived of as less willing to be involved in decision-making [1, 15]. Consequently, this poses a risk to keep the provider-patient hierarchy that traditionally have been held in healthcare. Holman and Lorig [3] concluded that healthcare professionals need to take on the role of teachers to empower patients with chronic diseases, and to help them develop self-management skills, so they can cope with their diseases. However, this task of empowering can be a difficult balancing act, requiring that healthcare professionals are responsive to their patients' abilities and desires to be involved [9].

The competence of the healthcare professionals also influences interactions, and the participants in our study questioned the COPD-related competence and interest among healthcare professionals. Our previous study [15] and a recent systematic review [37] showed that healthcare professionals sometimes felt they themselves lack competence in supporting self-management, or they considered self-

management to be outside their daily practice, and therefore they chose to refer patients to others for support. The access to pulmonary rehabilitation in Swedish primary care is rather low [15, 43], and the organization (management in primary care) must provide opportunity for its healthcare professionals to feel competent enough and have time to educate and support empowerment among people with COPD.

Implications

In line with the conceptual framework presented by Stewart et al. [9], our findings show that decision-making, interpersonal style and communication were all crucial in how the participants experienced the interaction. However, there are several challenges for interactions between people with COPD and healthcare professionals in primary care. Primary care and healthcare professionals have important roles in interactions with people with COPD, and shared decision-making, interpersonal style and communication must be improved to support empowerment among people with COPD. One option for improvement in these three dimensions would be a jointly elaborated individualized treatment plan that includes advice about actions to be taken in the event of an exacerbation. Such treatment plans are seldom used [1, 15, 44], and few Swedish primary care centers report that their routines support the development of such plans for patients with COPD [45], despite the fact that individualized treatment plans are recommended by national guidelines [46]. People with COPD who have received individualized treatment plans have been shown to be more likely to know more about COPD, to comply better with treatment, to generally have improved health, and have reduced readmissions [44, 47, 48]. For those reasons, jointly elaborated treatment plans should be a priority for the healthcare organizations.

Methodological considerations

During the various components of the current study – design, data collection and analysis – we have striven for trustworthiness [22] in line with the four criteria presented by Charmaz [16]. First, *credibility* [16] was strengthened by variation among participants regarding sex, urban/rural living areas, work situations and perceived symptoms from COPD. However, despite the considered theoretical saturation [16], the sample was relatively small and studies in other context may add valuable perspectives. One limitation was that our study had little ethnic variety, as it was difficult to find immigrants with COPD who could be interviewed in Swedish. A person who cannot speak the language risks being in an even more dependent position, and it would be very valuable to explore the experiences of such persons. Credibility was also striven for through systematic comparisons between transcripts of the interviews and the emerging categories. Second, the created theoretical model met the *originality* criteria [16], because it offered new insights about how people with COPD experience interactions in primary

care and how these interactions influence self-management and disease coping. Third, the study offers *resonance* [16], because our findings portray the full picture of the participants' experiences of interactions with healthcare professionals in primary care. Several of our findings are similar to those in groups of people with other chronic conditions, which strengthens the resonance. Finally, this study may be *useful* [16], as it offers information that can be used by primary care providers to improve patient management of COPD both nationally and internationally. Our findings about the influence of interpersonal style on coping and self-management also seem to match the experiences of people dealing with other long-term conditions [49–51], and we hope that our findings can help improve management of several long-term conditions in primary care.

In addition to inclusion of different ethnicities mentioned above, another direction for future research would be to apply gender perspectives in the analysis. Earlier studies of COPD management have reported a gender bias in healthcare concerning diagnosis and treatment [52–54], and there is a great need to further explore gender aspects in interactions with healthcare professionals in primary care.

Conclusions

This is the first study to explore how people with COPD experience interactions with healthcare professionals in primary care, and how these interaction influence self-management and disease coping. Our main result, including the generated theoretical model, suggests that people with COPD experience these interactions as ambiguous, because these interactions can enhance confidence for self-management with empowering support, and at the same time they can also stigmatize and threaten, which is disempowering. A patient-provider relationship that is characterized by respect and regularity, along with a personal positive and accepting view on the diagnosis of COPD, is important for patient empowerment, self-management, and acceptance. By contrast, feeling as though COPD is a low priority disease and being met with negative attitudes and insufficient support, along with feelings of fear, shame and guilt, is disempowering and can inhibit healthcare seeking and other self-management activities. Healthcare professionals in primary care have a crucial role in empowering people with COPD by involving them in decision-making. In order to strengthen the possibilities for enhancing empowerment, COPD-related competence among healthcare professionals, and their understanding of the value of regular, respectful and empowering interactions must be increased. The findings from this study could help healthcare professionals in primary care to plan and implement self-management support for people with COPD and other long-term conditions.

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Disclosure of interest

The authors report no conflict of interest.

Data availability

Quotes supporting the findings are available within the manuscript. Additional quotes from the transcripts are available from the corresponding author on reasonable request. However, entire interview transcripts will not be shared to ensure confidentiality, and since consent for this have not been obtained from the participants neither from the Regional Ethical Board.

Author contributions

KW, SL and MT contributed to the planning and design of the study. SL and MT collected the data. SL performed the analysis in recurrent discussions with MT and MW. KW was involved in discussions of the final analysis and model. SL was main responsible for writing the manuscript in cooperation with all authors; and all authors contributed to the revision and approved the final manuscript.

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