

EMPIRICAL STUDIES

Living with an ever-present breathlessness: Women's experiences of living with chronic obstructive pulmonary disease stage III or IV

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Abstract

Background: Living with chronic obstructive pulmonary disease stage III or IV has a major impact on a person's everyday life. This qualitative study focuses on women with chronic obstructive pulmonary disease stage III or IV.

Aim: The aim of this study was to describe women's experiences of living with chronic obstructive pulmonary disease stage III or IV.

Method: A purposive sample of fifteen women with chronic obstructive pulmonary disease stage III or IV participated in the study. Data were collected through individual semi-structured interviews that were subjected to qualitative content analysis.

Findings: One theme was identified, stabilizing an ever-present breathlessness by restoring strength, and three categories are as follows: managing a restricted everyday life as an expert of their illness, being afraid of contracting infections leading to suffocation and suffering and importance of continuous help and support from significant others and digital media. Breathlessness restricted women with chronic obstructive pulmonary disease, living with a body they have to wait for. Managing everyday life was adapted to their limited abilities and energy. This required detailed planning, good knowledge of their breathing and body. Women were afraid of contracting life-threatening infections that caused suffering, especially COVID-19. The fear leads to isolation and digital media was described as an important means of communication. Significant others gave support and help that was practical and emotional. Women with chronic obstructive pulmonary disease experienced lack of continuous help and support from healthcare professionals.

Conclusion: Stabilizing an ever-present breathlessness by restoring strength required women with chronic obstructive pulmonary disease stage III or IV to conduct detailed planning to manage everyday life. Being afraid of contracting infections and the consequences of suffocation had increased since the pandemic COVID-19 outbreak, which led to self-isolation and an inactive everyday life. To get help, support and socialize, women used digital media.

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KEY WORDS

chronic obstructive lung disease, continuity of patient care, fear, infections, nursing evaluation research, qualitative research, social isolation, social support, suffering, women

BACKGROUND

Living with a long-term illness such as chronic obstructive pulmonary disease (COPD) means living an everyday life restricted by breathlessness and frequently prolonged upper respiratory tract infections [1]. Women's experiences to live with COPD are described in some previous studies [2–5]. According to Steindal, et al. [2] women felt safe having a plan in case of deterioration and strategies to prevent dyspnoea. Women with COPD wanted education, supervision and healthcare professional that knew their story. Something that helped women to live with the illness was social relationships and the possibility of meaningful activities, this could promote the feeling of connectedness. O'Neill [3] stated that women with COPD struggled with burdensome symptoms, loss of jobs, social activities and family relationships. For women with COPD coping strategies were navigated by the symptoms of dyspnoea, fatigue and anxiety for infections. Women restricted their activities to avoid deterioration by, for example weather extremes, tobacco smokes and meeting people. Women with COPD felt stigmatized as they described that society may consider COPD as self-inflicted and as a consequence women were reluctant for seeking care. Jonsdottir and Jonsdottir [4] described that women with COPD experienced being caught in a spider web related to relapsing to smoking habit. According to research by Nykvist, Larsson and Dahlborg-Lyckhage [5], a greater focus on the woman as an individual behind the physical symptoms was important when supporting smoking cessation.

Chronic obstructive pulmonary disease is characterized by persistent respiratory symptoms and airflow limitations. The disease is complex and heterogeneous posing challenges for both patients and healthcare professionals [6, 7]. The most common symptoms of COPD are breathlessness, fatigue and anxiety [8–11]. The Global Initiative for Chronic Obstructive Lung Disease [6] classifies COPD severity in four stages: stage I is mild, stage II is moderate, stage III is severe, and stage IV represents very severe COPD. The main risk factor is tobacco smoking. By 2030, COPD is expected to be the third most common cause of death globally. Life expectancy is lower among people with COPD than the average Swedish population [8] and COPD has developed into being more prevalent in women [9]. Among people with COPD, many have other chronic diseases, such as cardiovascular diseases, hypertension and diabetes [6].

Among people with COPD, good days and bad days alternate, and they experience ups and downs like a roller coaster due to breathlessness causing negative feelings. All of

this makes living hard work [12]. Living with COPD means struggling for a couple of hours in the morning to be able to function to perform daily activities. Daily struggles can lead to constant worrying about being able to function normally and to move, to walk or sometimes to speak [13]. Like many serious illnesses, COPD is a mild disease initially, but it is progressive and currently incurable [6]. The nature of COPD often makes it difficult to determine if the person has reached the end-of-life stage [14]. At the end of life, social, existential and physical priorities are described as being important issues among older people with COPD [15]. After exacerbations, which can be life-threatening, people can feel fear, anxiety and uncertainty about their future [16] and exacerbations are known to have a negative influence on the well-being of people with COPD [13]. Fear of dying is defined as the fear of suffering physically and fear of the dying process. Among people with COPD, fear of suffocation and awareness of death have been previously described [17, 18]. According to Johansson, et al. [19], the symptom burden causes an altered daily life among people with COPD stage III or IV, and they express their need for support and have strategies to manage their everyday lives. Pulmonary rehabilitation enhances the sense of support among people with COPD, and it is beneficial in improving health-related quality of life and physical activity and reducing symptoms [20]. According to Gardener, et al. [21] people with COPD describe their own perspectives regarding their support needs as physical, psychosocial and social support, including emotional regulation to thrive despite their illness. As well as the development of relationships and service, navigating in information about maintaining independence revealed 13 domains. These domains could enable individual care for patients with advanced COPD to identify and express their individual support needs. Continuity of care is associated with supportive needs being met [22]. Continuity of care entails information exchange, management of people's illness and interpersonal relationships [23], as well as sustained continuity of care that improves quality of life for persons with long-term illnesses [24]. Striving for continuity and normality has been described as a salient aspect in previous research of living with chronic illnesses [25]. People with COPD have experienced living with stigma as causing feelings of guilt, blame, shame and hostility, and that society may consider COPD as self-inflicted [26, 27]. This may result in making women reluctant to seek care. Primary healthcare is also less likely to recognize COPD in women [28].

A review of the literature indicates that the knowledge concerning women's experiences of everyday life with COPD stage III or IV, is sparse. To the best of our knowledge,

women's experiences about their everyday life with COPD in the stage III or IV are not described in previous studies. This study was conducted during the COVID-19 pandemic and thereby gives insight into women's experiences during this pandemic situation. Knowledge about women's experience gives opportunities to meet their needs and thereby supports their health and well-being. Thus, the aim of this study was to describe women's experiences of everyday life with COPD stage III or IV.

Method

Design

This study has a qualitative descriptive design, as the aim is to describe women's experiences living with COPD stage III or IV. Semi-structured interviews were performed and subjected to qualitative content analysis according to Graneheim and Lundman [29]. The analysis is both at manifest (categories) and latent (theme) level and conducted without preconditions (cf. Graneheim and Lindgren [30]).

Context

This study was conducted in a region in the middle of Sweden with a population of 245 000 inhabitants [31]. The estimated prevalence of COPD for all stages in Sweden is between 500 000 and 700 000 individuals and the prevalence for individuals living with stage III or IV is approximately 6% [32, 33]. The pulmonary medicine department at a hospital in the region was contacted for recruitment of participants for the study.

Participants

A purposive sample of 15 women with COPD stage III or IV participated in the study. According to Patton [34] a purposeful sampling is to select information-rich cases whose study will illuminate the research questions in depth. The inclusion criteria for being included were age >18 years old, being diagnosed with COPD stage III or IV, speak and understand Swedish. The participants were aged between 50 and 84 years (median = 75 years) and had been diagnosed with COPD between 2 to 30 years (md = 12 years). Seven women had oxygen treatment at home. Four women had a secondary school education, seven had completed high school and four had some higher education. Fourteen women were retired or had early retirement; one woman had a part-time job. Most of the women lived alone, while five women were married or lived with a spouse. Most of the women lived in a flat

and one woman lived in a nursing home. Four women had homecare service. The participants lived in rural or central parts of the region.

Procedure

The head of the pulmonary medicine department at a hospital in the region gave permission to assist with recruitment of participants for this study. A secretary distributed invitation letters based on the inclusion criteria to women with COPD stage III or IV. They received information about the study, an informed consent form and a reply form. Fifteen women gave permission to participate and were contacted by phone by the first author and an appointment for an interview was made.

Interviews

Individual semi-structured interviews [35] were conducted with the participants. The participants were asked questions about their experiences of living with COPD stage III or IV. An interview guide was used containing questions such as Please tell me about your everyday life ...? and Could you tell me about your contacts with healthcare professionals? Clarifying and encouraging questions were asked, including Can you tell me more about that? and Can you give an example? The interviews lasted between 32 and 118 minutes (md = 60 minutes), were digitally recorded and were transcribed verbatim. The interviews were conducted by the first author during March–May 2020 by telephone due to the COVID-19 pandemic.

Data analysis

The interviews were analysed using qualitative content analysis according to Graneheim and Lundman [30]. The analysis started with several readings of the interview texts to gain a sense of the content. In the next step, meaning units were identified guided by the aim of the study. The meaning units were condensed, coded and sorted into categories based on similarities and differences in content (Table 1). The categories were compared, and a theme was identified, that is, threads of meaning which appear in category after category (cf., 36 p. 250). The transcript was then reread to refine and verify the categories and the theme.

Ethical considerations

This study was conducted in accordance with the Declaration of Helsinki [37]. Before the interviews started, the participants

TABLE 1 Example of the analysis process

| Theme | Stabilizing an ever-present breathlessness by restoring strength | | |
|--|--|-----------------------|--|
| Meaning unit | Condensed meaning unit | Code | Category |
| I can tell you about any of my days, I get up in the morning, and then I go to the bathroom and pee, wash my hands, and then I sit down. I breathe calmly. I take my medications, wait about 30 min between inhalations. Then I just sit and wait for my breath to be stable until I can go on and get washed and dressed. Then I go to the kitchen and have breakfast, but I have to stop halfway to the kitchen and sit down and catch my breath... (P3) | I get up, go to the bathroom, sit down and breathe calmly. Waits 30 min between inhalations. Sit and wait for my breath. Get dressed. Go to the kitchen for breakfast, stop halfway to catch my breath | Waiting for my breath | Managing a restricted everyday life as an expert of their illness |
| If I get corona, put me down with morphine. Finish me off so that I don't have to feel these disgusting suffocating feelings because I've felt them a few times before (P5) | If I get corona, finish me off, so I don't have to feel suffocation | Afraid of suffering | Being afraid of contracting infections and consequences of suffocation and suffering |
| I am in a group on FB called alphetrypsin 1 COPD. You can track a little and actually get knowledge... I hear that some people have contact nurses and physicians for their COPD. I have not ever had anyone special (P14) | In the group on FB you can get knowledge, they have special nurses and physicians for their COPD, I have not ever had anyone special | Continuity | Importance of continuous help and support from significant others and digital media |

received oral and written information about the study. They were guaranteed confidentiality and an anonymous presentation of the findings. Furthermore, the women were informed that their participation was voluntary and that they had the opportunity to withdraw at any time during the study without providing any explanation. All participants signed a consent form prior to the interviews. Approval for the study was obtained from the Ethical Review Agency in Sweden (Dnr. 2020-00085).

FINDINGS

The analysis resulted in one overarching theme, stabilizing an ever-present breathlessness by restoring strength, with three categories.

Stabilizing an ever-present breathlessness by restoring strength

The theme consists of three categories, managing a restricted everyday life as an expert of their illness, being afraid of contracting infections leading to suffocation and suffering and importance of continuous help and support from significant others and digital media.

Managing a restricted everyday life as an expert of their illness

Women with COPD described that they had to manage a restricted everyday life by knowing their breathing and body well, they could balance activities and rest to get control. The basic needs of everyday life demanded scheduling according to their breathing rhythm. Participants described that unscheduled activities caused them severe breathlessness, leading to feelings of panic, stress and frustration. These situations could arise from going to the bathroom or getting dressed too fast. The participants used their own expertise of their illness managing everyday chores.

I can tell you about any of my days, I get up in the morning, and then I go to the bathroom and pee, wash my hands, and then I sit down. I breathe calmly. I take my medications, wait about 30 minutes between inhalations. Then I just sit and wait for my breath to be stable until I can go on and get washed and dressed. Then I go to the kitchen and have breakfast, but I have to stop halfway to the kitchen and sit down and catch my breath...

(P3)

Many participants described having problems managing their personal hygiene such as washing their hair. Women with COPD described that walking from one room to the next or climbing stairs caused severe breathlessness. They expressed that holding their arms above their heads, such as hanging up their laundry, was extremely draining. Participants described that decreased appetite could be an obstacle, eating, preparing meals and the smell from cooking could trigger severe breathlessness. Housework, such as cleaning windows one at a time or unloading the dishwasher in stages, reduced breathlessness. If their body was in shape, they could do housework or visit a friend.

Before, I was cooking and baking and made large quantities of food but nowadays I can't handle the stir....it makes me breathless

(P5)

Participants described enabling managing their personal bodily needs in their everyday life by being the expert of self. Women with COPD described that physical aids reduced problems managing their daily life. They got out for longer walks by having a walker, were able to manage hygiene with a shower chair and slept more comfortably with an adjustable bed. Women in need of oxygen treatment described life as better when using the portable oxygen. This enabled women to participate in everyday life activities, which also prevented isolation. The women described how limited energy contributed to isolation even though they had the ambition of participating in activities. Meaningful amusement at home was to solve puzzles or watch TV. Women with COPD described the value of physical activity in stabilizing their illness. However, physical activity was challenging, and women tended to plan and prioritize after-lunch sessions because their lungs felt stiff during the mornings. The most common activities for participants were taking walks, doing water gymnastics and doing sit-down exercises. Participants described that different weather conditions, such as cold, moist and hot weather could affect breathing and be an obstacle to performing outdoor activities.

Even if I just walk 50 meters... then I must stop to catch my breath. However, you can get quite far if you walk 50 meters and then 50 meters again and again

(P12)

Having a positive outlook on life helped women with COPD manage to do things they wanted to and sometimes just to endure. Participants talked about trying to live more in the present and accepting the disease progression. Some

women with COPD described mood alterations as occurring due to loss of abilities and some admitted to feeling grief due to loss of abilities. In case of deterioration, women with COPD described managing by using breathing techniques and evaluating whether they needed corticosteroids or antibiotics. Many of the participants were equipped with a stand-by prescription.

Being afraid of contracting infections leading to suffocation and suffering

Women with COPD described that they were afraid of being affected by infections as an infection could lead to potential life-threatening consequences. During the past nine months, many participants had been hospitalized due to exacerbations secondary to bacterial or viral infections. The participants said that they now lived with social distancing and isolation, as measures they already had incorporated in their everyday lives. Women with COPD described an ongoing inner dialogue about what would happen to them if they got an infection.

If I catch a cold, I'm terrified of it. I get pneumonia and mucus and cough, and I get really, I can cough and have mucous for several weeks

(P12)

Although women with COPD needed help, some women told how they had dismissed homecare out of fear of the pandemic outbreak. Most women with COPD explained that their thoughts were consumed by terrifying feelings and about death. They were certain that it would cause their death if they became infected by COVID-19. If it would come to a life-threatening situation, they wanted to avoid suffering. Everyday life consists of an ever-present breathlessness and their previous experiences of the feeling of suffocation had led to the decision to avoid suffering when, or if, infections of any kind occurred. The women talked about how they did not want to feel anything and if it ever came to an end-of-life situation, they also mentioned medication suggestions for themselves. A few women had previously talked about death with their close relatives, but due to the pandemic, this topic had become urgent. In case they were to need respirator care, a few women had decided and documented in their medical records together with healthcare professionals not to allow it. The women themselves had communicated these decisions to their close relatives.

If I get corona, put me down with morphine. Finish me off so that I don't have to feel these

disgusting suffocating feelings because I've felt them a few times before

(P5)

Importance of continuous help and support from significant others and digital media.

Women with COPD described how relations with significant others (i.e. family members, medical professionals and others) enriched their everyday life. Participants said that there was great importance in the continuous relations for help and support from both healthcare professionals and significant others. They explained that social media and discussion forums were supportive in terms of exchanging advice regarding medicines and care in other parts of Sweden. Furthermore, challenging topics could be discussed in this way, such as mortality in case of deterioration. The participants talked about the importance of accompaniment, whether it was face to face or, during the pandemic COVID-19, digitally or by phone.

I learn a lot about medicines on the Facebook-group where others suggest medicines and if I want to, I can suggest those to my physicians

(P10)

Women with COPD described how the support and help from significant others was very important. Some women lived with spouses who had to perform everything the women could not do themselves in their daily life. There were also women with COPD who lived alone and have close friends as a prominent supporting factor.

In my house there is an inner yard, I've six neighbours and they are so very nice to me. They help me shop, wash my laundry and help me to get out in the yard – so one must be grateful too

(P7)

In case of a need for contacts with healthcare professionals, most of the women described encounters with healthcare professionals in positive tones. In-patient care was described as sufficient for most of the participants. Encounters such as physicians giving information about new easy-to-use medicines enabling uniform breathing were described positively. A few women described care encounters in negative terms, in particular with physicians due to smoking cessation efforts. Some women with COPD described their significant other's attitudes about COPD as a self-inflicted disease linked to previous smoking. These women described how significant

others or other people reacted to the smell of burning cigarettes. Two women who were in bad shape and under investigation for a lung transplant expressed their fear that they already lost their chances for survival due to previous smoking. Moreover, the participants described experiences of labelling and being compared with persons living with HIV or addicts by other people in society, if they talked about their disease. The participants expressed their feeling that the disease was shameful and unlovely compared to, for example, asthma.

I feel ashamed about this as I can imagine those with HIV are feeling. Because it was unpleasant to get COPD. Then you have to blame yourself because you have smoked

(P3)

Many women with COPD described that they lacked continuity with healthcare professionals. Therefore, by being the expert of stabilizing an ever-present breathlessness by restoring strength, participants were afraid of not receiving correct care or were reluctant to listen to advice. To feel safe, women wished for improvements in the continuity of care, and to be judged only by a COPD expert. Women with COPD promoted individualized care and wished to be seen as a whole person, not being focused on just for medical matters. Some participants questioned follow-up care routines and a few experienced, for example, that auscultation of their lungs was neglected. In addition, women described visiting primary care as anonymous and that physicians did not read their medical records. Due to women with COPD experiencing a lack of continuity, the women had to retell their life story at every visit.

I am in a group on FB called alphasitrypsin 1 COPD. You can track a little and actually get knowledge... I hear that some people have special nurses and physicians for their COPD. I have not ever had anyone special

(P14)

Women with COPD who received municipal care and homecare also complained and described that there was no continuity of the healthcare professionals. These participants expressed a sense of despair because they often found that the healthcare professional lacked education and enough knowledge of the basic hygiene aspects of COPD.

I had to tell one of them to put on gloves. It's like you always must check what they are doing

(P2)

DISCUSSION

This study aimed to describe women's experiences of living with COPD stage III or IV. The main findings describe that women experienced an ever-present breathlessness that is altering from ever-present to severe and back to ever-present, but stabilized by restoring strength. This severely restricted their everyday life and required detailed planning based on daily health variations. According to Eriksson [38], suffering of illness is illness related when originated from a disease or its treatment, as well as having a disabled body. Participants feared suffering the consequences of infections and avoided contraction. Expressions of suffering were related to the illness and had various faces, physical, emotional and losses. Further, digital support and significant others were described as important for alleviating suffering of illness [39].

Previous research about women's experiences in different stages of the COPD illness [2–5] have similarities to the findings in this study but also differences. Steindal et al. [2] reported that women felt safe having a plan in case of deterioration, in contrast women with COPD in this study expressed using their own expertise assessing needs in this situation. Women with COPD described situations in everyday life when they had to manage feelings of panic, stress, limited energy and frustration due to severe ever-present breathlessness. Limited abilities became a struggle between wanting to and not being able to do things. This aligns with earlier research showing that a lot of time was consumed by waiting for their body to be able to function [40, 41]. People with COPD expressed trying to endure living with the consequences of breathlessness, use positive psychological coping strategies and accepting loss of independence [2, 42–44]. Women's normal functions of breathing gradually turned into being ever-present following loss of abilities and independence. Loss of bodily abilities leads to increased dependency. This could be compared to suffering of illness represented in women's expressions of a deteriorated body [38]. Even though ever-present breathlessness is painful, the participants expressed the importance of managing life being positive doing everyday chores. Additionally, Steindal [2] stated the importance of activities and similar to women with COPD in this study highlighted the importance of physical activity adapted to their capacities and satisfaction after activities. Research [19, 45, 46] has shown that physical activities are important for people with COPD.

This study found a relevant connection not previously described, between an ever-present breathlessness and fearing contracting infections. Many participants had recently been hospitalized due to exacerbations secondary to infections. During the COVID-19 pandemic, this fear became even more terrifying, bringing up thoughts about their own death and how to avoid suffering through suffocation. Women had concerns about what would happen if they became infected by COVID-19 and experienced lack of information from

healthcare. Research [12, 21] has shown that people with severe COPD have concerns regarding death and dying.

Participants with support from homecare experienced this as insufficient and experienced dependency caused by the discontinuity of their careers. Due to this effect, women with COPD cancelled homecare as a precaution because they were afraid of COVID-19. Their emotional suffering [38] was expressed worsened due to the pandemic COVID-19 and the potential consequences. Morse [47] noted emotional suffering and enduring not being linear, rather in a movement back and forth and this seems to fit well with our findings describing an fluctuating ever-present breathlessness and being afraid of infections.

Digital media has transformed the communication channels for people in general, and for patients in particular [48]. Nigel et al. [49] found that the most frequently discussed topic by people with COPD on social media was cough, mucus and dyspnoea. Women with COPD found that continuous help and support from significant others and digital media was important. The main topic for discussions on social media was about the COVID-19 pandemic and the importance of actually having conversation with close relatives about death. Similar to our results, Ali, Fors and Ekman [13] stated that people with COPD considered it helpful to share their experiences and listen to other people's thoughts about their illness. Communicating at a distance using digital media seemed appreciated in terms of support among people with COPD. Women with COPD expressed that practical support was positive, but emotional and social support was of the highest importance. Social media and websites were empowering and useful discussion forums especially after the digital paradigm shift due to the pandemic COVID-19. Women described using digital media to exchange knowledge or to discuss challenging topics with other people with COPD, as well as receiving helpful support that offered continuous accompaniment and reduced isolation. Digital meetings with people that are in the same situation means a communication based on a shared understanding that significantly seems to reduce suffering of illness for women in this study.

Research [4, 5] found that smoking cessation is challenging and support for women should have an individual focus. Women with COPD promoted individualized care and to be seen as a whole person in all contacts with healthcare professionals. Instead, they expressed discontinuity, lack of follow-up and of specialized nurses (cf. 50). Moreover, women with COPD experienced being labelled by members of society who compared them with people living with HIV. Studies [3, 51] have shown that people with COPD experienced social accusation meaning that the illness was self-inflicted and therefore suffered feelings of shame and blame. They felt having no right to complain, only to accept the consequences. This is according to Eriksson [38] an expression of suffering of illness.

Methodological considerations

The results from this study cannot be generalized, although transferred to other similar diagnoses and contexts. To achieve trustworthiness, a purposive sample was used based on inclusion criteria. The sample was based on a model of sample size in the qualitative selection and information power [52]. This method determines the appropriate number of participants needed concerning the information generated by the sample. Fifteen women were recruited. This number was considered sufficient and allowed studying various women's experiences of their everyday life with COPD. The sample size in qualitative research should be large enough to achieve variations in experiences and include rich data while remaining small enough to permit a deep analysis of the data [34].

Reflexivity comprises the researcher's background, experience, education, and the way the researcher engages in data collection and analysis [35]. The first author is a PhD student, two of the authors are senior researchers, and all authors have wide experience of care for long-term illnesses.

To accomplish trustworthiness in the analysis, the authors moved back and forth between the interview text, meaning units, condensed meaning units, codes, categories and theme, until an agreement was reached by all authors [30]. In striving for credibility, quotations were selected from the interview text presented in the result section [31]. The first author conducted the interviews. A pilot interview was conducted to test the interview guide, and the testing did not involve any changes to the guide. There were limitations. The shortest interview lasted 32 minutes but was rich in content.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The findings of this study of women's suffering of illness are visualized by their ever-present breathlessness. Women with COPD stage III or IV are often living with a severe and ever-present breathlessness that restricts everyday life extensively. They are frightened of suffering if they would get a potentially life-threatening infection, and try to avoid them by practicing self-isolation. Support from close relatives is very important for women with COPD, but the participants highlighted that they lacked continuous support and help from healthcare professionals. Digital support could be suitable for women with COPD especially due to their fear of infections. Women with COPD use digital media for help and support, but healthcare professionals are not yet offering such support. As digital media enables safe and continuous help and support for women with COPD in contact with healthcare professionals, E-health could be an area for further development to provide care.

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CONFLICT OF INTEREST

None declared.

AUTHOR CONTRIBUTIONS

Ekdahl, A performed all the data collection. Ekdahl A., Söderberg S. and Rising-Holmström M. performed the analysis, designed the study and contributed to the writing of the manuscript. All authors read and approved the final manuscript.

ETHICAL APPROVAL

Approval for the study was obtained from the Ethical Review Agency in Sweden (Dnr 2020-00085).

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