# ORIGINAL ARTICLE

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# Living with the risk of being infected: COPD patients' experiences during the coronavirus pandemic

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### Abstract

**Aims:** To explore the existential significance of living with the risk of being infected with coronavirus in patients with COPD.

**Background:** Distancing measures aim to break the coronavirus transmission chains. Physical separation from social networks and social isolation are correlated with anxiety and depression. People with a chronic obstructive lung disease are particularly vulnerable due to the increased risk of a serious course of illness, so therefore many of them choose self-isolation to protect themselves from COVID-19.

**Design:** A qualitative exploratory study using individual semi-structured interviews.

**Methods:** From June–September 2020, 13 participants were recruited through advertisements on Facebook as a convenience sample for semi-structured individual interviews. The interviews took place through virtual platforms or in physical meetings. Data were analysed using Ricoeur's phenomenological approach, involving naïve reading, a structural analysis and a critical interpretation strategy. The study has been reported in line with COREQ guidelines.

**Findings:** Living with the threat of being infected with coronavirus has greatly affected everyday life for patients with COPD. The nagging fear of coronavirus as a death threat was a dominant feeling, together with anxiety, loneliness and hope. With self-isolation, followed concerns of being forgotten and thoughts of the future, balancing between fearing the worst, and hoping the best.

**Conclusions:** Patients with moderate to severe COPD feel compelled to self-isolate, as they fear dying from COVID-19. The study revealed a need for proactive contact with health professionals to calm the patients' feelings of deprivation, loneliness, hopelessness and anxiety.

**Relevance to clinical practice:** Information about the patient's perspective may be used to develop targeted interventions aimed at giving adequate information, supporting hope, implementing digital or virtual solutions to keep in contact and avoid the feeling of being alone and forgotten during a pandemic crisis.

#### KEYWORDS

COPD, coronavirus, COVID-19, fear, hope, patient perspective, qualitative interview, selfisolation

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# 1 | INTRODUCTION

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The outbreak of a novel coronavirus disease, later known as COVID-19, started in China in December 2019 and guickly spread to neighbouring countries and subsequently to the rest of the world. In March 2020, the World Health Organization (WHO) declared the situation to be a pandemic with millions of infections and nearly 1 million deaths worldwide (WHO, 2020). At present, vaccines to combat the COVID-19 disease are under development. Social and physical distancing measures are still recommended to slow the spread of disease by breaking the coronavirus transmission chains and preventing new ones from appearing. These policy measures to curb the pandemic have changed everyday life for many people (WHO, 2020). Isolation, involving a lack of contact with, or physical separation from, family, friends or broader social networks, plus the lack of involvement in social activities, and for some people social isolation, is correlated with loneliness (Brooke & Jackson, 2020). In particular, people with a critical chronic disease, such as a severe lung disease, are living with a potential life-threatening infectious virus (Wu et al., 2020). Although COVID-19 does not affect everyone in the same way, patients with moderate to very severe chronic obstructive pulmonary disease (COPD) are vulnerable to COVID-19, and they are conscious about the potential need for intensive care and treatment (Hansen et al., 2020).

# 2 | BACKGROUND

As the number of infected people increases on several continents, some people are particularly at risk of being infected with coronavirus. People with chronic diseases, such as severe heart disease, lung disease, kidney disease, liver disease, impaired immune system, advanced dementia and poorly regulated diabetes, and people with old age and severe obesity, are particularly vulnerable, due to the increased risk of a serious course of illness requiring hospitalisation and intensive care (Wu et al., 2020). The main measures to minimise the spread of infection in a population without immunity is to ensure good hand hygiene, coughing etiquette and keeping a physical distance between people and staying at home. Moreover, shielding and protection for vulnerable groups are important protective measures against COVID-19 (WHO, 2020). Even though great efforts are being made to develop vaccines against the coronavirus to protect against the COVID-19 disease, access to a vaccine will probably be limited in the short run (Neumann-Böhme et al., 2020). The worldwide corona pandemic has created unpredictability, fear and death, not only within the healthcare system, but also in the entire world population (Hansen et al., 2020). The coronavirus causes upper respiratory infection which in turn causes more severe symptoms like high fever, severe cough, and shortness of breath (Ustun, 2020). This is one of the reasons why people living with COPD are at increased risk of severe illness from coronavirus (Wu et al., 2020). Patients diagnosed with moderate to very severe COPD are used to being challenged by respiratory symptoms, infection risks and they

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

- This study contributes insights into the importance of warm distancing when taking care for patients with COPD during a pandemic health crisis.
- This study provides a comprehensive understanding of COPD patients' burden of self-isolation during the coronavirus pandemic.
- Knowledge of the patient's perspective may guide the approach of health professionals in terms of proactive telephone calls or virtual consultations focusing on mental health.

often live an everyday life with limitations. As COPD progresses, symptoms such as shortness of breath, coughing, increased mucus production and fatigue often get worse (Singh et al., 2019). Learning to live with physical, mental and social limitations in everyday life is often achieved through formal patient education and through patients' experiences in everyday life (Baker & Scholz, 2012). However, COVID-19 is a new and frightening additional threat in many people's everyday life. Some patients are more vulnerable than others to the psychosocial effects of pandemics (Pfefferbaum & North, 2020). Living with an increased risk of severe illness from coronavirus in everyday life may require new initiatives from nurses and other healthcare professionals. However, we need to know more about the patients' point of view to identify their worries and struggles to identify their needs. We aimed to explore the existential significance of living with the risk of being infected with coronavirus in Danish patients with COPD.

## 3 | METHODS

Using a qualitative research strategy, we addressed the following questions: (a) What worries do patients with COPD experience with regard to living with the risk of getting infected with coronavirus? (b) How do patients with COPD deal with the risk of being infected? (c) Have any new needs (psychical, psychological, social and/or existential) arisen? We conducted semi-structured individual interviews with patients living with moderate to very severe COPD. In preparing and conducting the interviews, we were inspired by Kvale and Brinkmann's (2015) descriptions of the semi-structured life world interview, as we wanted to understand the existential significance of living with the threat of being infected from the patients' point of view. The research interview is a professional conversation "where knowledge is constructed in the interaction between the interviewer and the interviewee" (Kvale & Brinkmann, 2015, p. 4). Through individual interviews, we asked questions about the patients' lived world and listened to their dreams, fears, hopes, views and opinions in their own words. The 32-item consolidated criteria was used for

reporting qualitative research (COREQ) to ensure methodical rigour (Tong et al., 2007) (Appendix S1). In addition, we conducted regular research meetings to discuss the data analysis, sampling methods and data generation. The research team included two registered female nurses (associate professors, PhDs) with a background in research, respiratory and pulmonary care and home care nursing.

#### 3.1 | Context

In February 2020, Denmark detected the first case of COVID-19. In the following weeks, the pressure of infection rapidly increased and in March 2020, the Danish Government decided to close down the country. Closing down Denmark was followed by almost daily press releases shown on national television, in which the government, the health authorities and/or the police authorities presented updated threat levels, recommendations and restrictions to stop further infection and reduce the infection pressure. Like in many other countries, the Danish borders were closed. Grocery stores, pharmacies and other vital stores could still remain open, but with extensive restrictions. Other shops, restaurants, bars, music venues, theatres, schools and educational institutions were closed down and people were encouraged to work from home when possible. Financial aid packages were negotiated in place, to avoid the expected economic collapse in the Danish society. The close down resulted in markedly decreasing infection pressure and the epidemic curve deflected. In April 2020, a cautious reopening of the country started. The opening was planned to take place in several phases and with continuous monitoring of the Danes' behaviour and the development in numbers of infection. The lockdown deflected the epidemic curve. but in October and November, the numbers increased again, and the risk of catching a coronavirus infection is almost the same as in March and April 2020. In Europe, we are in the middle of a 2nd round and it is still recommended to keep a two-metre distance from people whom we consider particularly vulnerable. In Denmark, approximately 100,000 patients receive medical treatment for COPD and approximately 50,000 Danes have severe or very severe COPD (Lange et al., 2012).

#### 3.2 | Sample and participants

We recruited participants in two specific COPD groups (one closed and one open) based on a convenience sample (Robinson, 2014), through advertisements on Facebook. Both groups had the stated purpose of sharing experiences and information about life with COPD. The members were mainly people with COPD, but also relatives were represented in the groups. The official invitation via Facebook was followed by information sent directly to the patients who had approached the researchers with an interest in participating in the study. In addition, all participants completed a statement of consent before participating in an interview. We collected data over a 3-month period, lasting from June–September 2020. The sample size was not predicted prior to the study. We continued to include participants as long as we were able to obtain additional new information and until further coding did not add new insights to the themes (Guest et al., 2006).

# 3.3 | Data collection

Kvale and Brinkmanns (2015) seven stages of an interview inquiry guided the interview method used in this study. Preparing the interview study included reflections in the research team on (1) thematising; (2) designing; (3) interviewing; (4) transcribing; (5) analysing; (6) verifying; and (7) reporting. To conduct a semi-structured interview is neither "an open everyday conversation nor a closed questionnaire" (Kvale & Brinkmann, 2015, p. 32). We developed a semi-structured interview guide that focused on certain themes and included suggested questions. The interview guide covered the following topics: Everyday life-before and now; Living with a potential threat; and New or changed needs. Each topic was explored through open-ended guestions, and the researcher had prepared supporting questions in case the informant did not understand the question, or if the answers were short and less detailed. As an example, participants were asked: "Please tell me about your thoughts when the prime minister closed the country down due to the spread of coronavirus?" Examples of sub-questions to elaborate on this question was: "How did the lockdown affect your everyday life?"; "What problems have you experienced?"; "What do you experience to be the biggest change in your everyday life?"; "What are your feelings about the future?". One of the trained interviewers conducted a pilot interview to test the questions in the interview guide. Data from the pilot interview were included in the study empirics.

In total, 19 patients with COPD responded positively to the Facebook invitation and asked for further information about the study. We sent information to their personal email addresses and subsequently 13 people (12 patients with moderate to very severe COPD and one spouse) chose to participate in the research project. As only one spouse signed up for the study, we chose to conduct 11 individual semi-structured interviews and one dyadic interview where a patient and his spouse participated together. We used the same interview guide in all the interviews. The participants were nine females (eight patients and one spouse) and four males (patients), all of Danish origin. The participants' ages ranged from 28-81 years (mean = 60). See Table 1 for more information about the participants. The participants came from different parts of Denmark, including both large cities and smaller villages. Due to the COVID-19 situation, the participants were free to choose whether the interview should take place physically or virtually. Some participants (N = 4) chose to be visited by the interviewer in their own home. Other participants (N = 2) chose to visit the research institution to participate in an interview, and more than half of the included participants (N = 7) chose to do the interviews through virtual platforms (e.g. licensed Skype for Business or Zoom). The first few minutes of an interview are decisive for the success of the interview (Kvale & Brinkmann, 2015). Through attentive listening, understanding

TABLE	1	Presentation	of	the
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	12	Male		13	Alone	Virtual
	13	Female		18	Alone	Virtual

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and respectful behaviour, the interviewer can manage to establish a good contact. The setting of the interview stage could, however, in our case, be threatened by technical challenges when the interviews had to take place virtually. Thus, in advance, we informed the participants that in case of technical problems, the research team was responsible for helping with a solution and we had a plan B if the virtual connection could not be established. In such cases, we had already agreed with the participants that the interview would be held over the phone.

Both the researchers were actively involved in conducting the semi-structured interviews. All interviews were recorded digitally and subsequently transcribed verbatim. Each interview lasted from 41–81 min (mean = 64 min).

#### 3.4 | Ethical considerations

The project was carried out in accordance with the Helsinki Declaration regulations and complies with the General Data Protection Regulations. According to Danish law, qualitative studies must be registered only if the project involves the study of human biological material, contains personally identifiable data or is part of a clinical trial. We chose a passive recruitment strategy on Facebook (Gelinas et al., 2017), which meant that we placed an invitation letter in the two selected Facebook groups with the aim of getting potential participants to contact the research team for more information and for consideration of enrolment. In the closed Facebook group, we gained access to the online COPD community by explicitly asking permission from a site administrator. We were very careful to make it clear that all further communication should take place by email or telephone, in order to avoid the participants revealing personal information on social media.

In writing, and through briefing and debriefing in the interview situation, we informed the participants about the purpose of the study and the procedures of the project, including voluntary participation, confidentiality and anonymity. In addition, it was possible to contact the researchers in writing or by telephone before participating in the study. All participants were mentally and physically able to understand and give informed consent. Identifiable information about the participating patients and spouses was anonymised within the manuscript. The authors have previous experience of conducting qualitative research and analysing qualitative data.

The researchers took into account ethical considerations regarding physical contact with the participants. The researchers took precautions to protect the participants from the coronavirus, which included social distancing and using hand sanitiser, as well as a medical facemask if required.

### 3.5 | Analysis

Both authors were involved in the analysis process, which was carried out using manual data management. Data were analysed using

#### TABLE 2 Illustration of the analysis process on the theme, "A nagging fear"

#### Units of meaning What was said

- "If I get infected I don't think I'll survive. You can hear on the news that the Coronavirus attacks the lungs. Those who have been ill and had problems with their lungs afterwards. Well, my lungs are bad enough as it is so I could end up not being able to breathe." (ID 1)
- "I don't even dare think about it because my lung capacity is only 20%, so I wouldn't survive it." (ID 2)
- "I actually talked to my lung doctor, and she said that in the case of someone like me they wouldn't even use a respirator because it damages internal terms. I didn't know that before, but now I do. So now I know that no one is going to make sure I can breathe if I get coronavirus [...] There is no hope for me and that terrifies me." (ID 2)
- "Of course I am afraid of getting it [COVID-19]], Because my lung percentage is so lo. I'd never survive it." (ID 3)
- "In a nutshell, the fact of the matter is that because of my illness I know very well that if I get COVID-19, there's a risk that things could go seriously wrong." (ID 7)
- "If I get corona, I'll die. That's what worries me. I'm pretty sure that if I get Corona I'll die because I've had a lung operation and because my lung percentage is as low as it is. So you might say that my situation is bad enough already [...] I'm simply afraid of dying." (ID 9)
- "A lot of doctors have told me that with the lung capacity I have, if I really got ill I wouldn't survive -I mean. for example, that I couldn't cope with being in a respirator [...] so it's no wonder I'm feeling terrified..." (ID 13)
- "I suppose I've been watching too much TV [...] in the end I just felt that I was an expert in corona and that didn't make me feel any better." (ID 11)
- 'I've seen all the press conferences on the TV2 News [national TV channel] and I've been reading stuff on the lung association website and I've discussed these things with my aunt. In this way I have tried to work out what it's all about and what it means for me." (ID 3)
- "We just messed around at home here, and talked about coronavirus all the time and saw all the news broadcasts. But then I thought I'd better stop watching all those news programmes because they simply made me feel worse." (ID 9)

Units of signification What was spoken about	Theme
A lack of trust in being able to survive COVID-19. In people suffering from COPD, coronavirus is perceived as a death threat	A nagging fear
The unknown factor—what coronavirus infection can lead to promotes fear	
When suffering from severe COPD, reduced treatment options trigger fear and the feeling of hopelessness	
Habitual poor lung function correlates with the fear of death	
COPD and COVID-19 will end badly	
A bad starting point activates the fear of death	
Reduced treatment options trigger fear and the feeling of hopelessness. Coronavirus is perceived as a death threat	
News broadcasts are a source of information and fear	
Seek knowledge to control fear	

Knowing too much from news broadcasts is a source of fear

Ricoeur's hermeneutic-phenomenological interpretation theory (Dreyer & Pedersen, 2009; Ricoeur, 1976, 2010). An inductive approach was used to understand the patients' experiences. The analysis and interpretation process consisted of three phases: naïve reading, structural analysis and critical interpretation and discussion. The naïve reading helped us obtain an overview and established a holistic understanding of the meaning of the experiences as articulated by the patients. After naïve reading, we began to formulate thoughts about the patients' experiences. In the process of carrying out the structural analysis, a number of units of meanings and significance appeared. These units were grouped according to their thematic content. The analysis revealed four themes. To enhance the quality of the analysis, both authors were involved in the analytical phases. In the presentation of findings, we use informative quotes to support the research team's analyses and themes. An anonymised informant ID number follows each quote. An example of the analytical process leading to the theme "A nagging fear" can be seen in Table 2.

# 4 | FINDINGS

Overall, the analysis showed that the existential significance of living with the risk of being infected with coronavirus greatly affected the everyday life of patients with moderate to severe COPD. The analysis revealed four themes: (a) Necessary self-isolation, (b) A nagging fear, (c) To be "the forgotten" and (c) The uncertain future.

#### 4.1 | Necessary self-isolation

The patients did not necessarily experience a correspondence between what the authorities recommended and what they themselves chose to do to minimise the risk of being infected with coronavirus. The authorities called for special attention to be paid to vulnerable groups in society, including patients with lung diseases. However, patients with COPD were not advised to stay isolated, but simply to pay WILEY<sup>-</sup>Clinical Nursing

special attention to keeping their distance, ensuring good hand hygiene and possibly staying away from rush hour in terms of both public transport and shopping in grocery stores. On the other hand, the patients experienced that it was imperative to go into self-selected home isolation in order to secure themselves in the best possible way against the risk of infection. The choice to self-isolate was relatively easy for the participants, as they did not think there was any alternative:

> We can't control the whole of society, we really can't. The only people who can look after us is ourselves. So that's what we have to do, as well as we can. (ID 7 + 8)

> I told the kids: I won't see you; I won't see anyone at all.

(ID10)

In the news and on the social media, they could hear and read about people who did not fear COVID-19 or even did not believe that the virus was a serious threat:

... I've been really frustrated about all these conspiracy sinners and the fact that people are deliberately pushing out false information. You know, people saying that the coronavirus is a con and just the tool of some political agenda [...] I have to admit that it makes me very bitter when people sit there and say that coronavirus is not real.

(ID12)

Moreover, the patients worried about people not following the authorities' warnings and restrictions. They were nervous both about becoming infected and about carrying the virus around to others if they were to continue to move around freely in society.

For those living alone, the burden was particularly heavy, as there was no one to talk to and socialise with. For those who lived with a spouse, there were other concerns. Especially in cases where the spouse either worked, had things to do outside the house or visited family and friends alone. In these situations, there was a fear that the spouse would bring the virus home to the isolated COPD sufferer. Both patients and spouses shared this concern, and some couples had even talked about moving apart during the coronavirus pandemic. In addition, a feeling of jealousy could arise:

> When he began to go shopping on his own [the husband], he might just decide to go for a little walk and pop round to visit the grandchildren. That made me feel sad.

> > (ID 4)

The patients said that long-term home isolation was making them 'crazy' and a few even talked about their home isolation as a jail-like situation. Many did not receive visits to their homes by either family or friends; just as only the most necessary help, from the home care services, for example, was welcomed into the home. Lack of physical contact with the immediate family was experienced as a great sacrifice for many of the patients and some even expressed it as a feeling of suffocating loneliness. Some explained that they were faced with a choice between risking dying from a COVID-19 or dying from lack of social contact:

... you can end up being so afraid of being in contact with other people that you die of loneliness.

(ID 11)

It was not only the patients, who refused to receive visits. In many cases, family members also did not want to visit, for fear of infecting their vulnerable mother, father or grandparents. Because of the lacking social contact, the patients expressed a feeling of skin hunger:

> ... you get skin hunger. It was almost a physical pain, a kind of desperate twitching in my body. [...] and you know I felt like committing a 'Corona crime', just going out and hugging everybody.

> > (ID 3)

Most patients had created new routines for talking to family and friends, as telephone calls, text messages and virtual calls via Skype or FaceTime were frequently used. Some found it very satisfying to talk to peers (other patients with COPD and lung diseases), for example on social media. Yet these forms of contact could not completely alleviate the need for physical meetings and the self-chosen isolation therefore affected the patients' psyche:

> But you can easily get lonely. It's like being a hermit, I'm a hermit. And that's not easy when you really enjoy the company of lots of other people.

> > (ID 13)

### 4.2 | A nagging fear

The patients expressed a belief that if infected with coronavirus they would surely die. Their already poor lung function, together with the risk of being infected with coronavirus, triggered anxiety and the fear of death. The patients feared ending up in the hospital needing mechanical ventilator treatment but without being offered it. If offered mechanical ventilation, they feared that they were not able to get out of it again. Hopes and beliefs of being able to survive coronavirus were not expressed. Patients feared for their lives and COVID-19 was regarded as a death threat:

> If I get infected I don't think I'll survive. You can hear on the news that the Coronavirus attacks the lungs.

Those who have been ill and had problems with their lungs afterwards. Well, my lungs are bad enough as it is so I could end up not being able to breathe.

(ID 1)

The patients explained that the TV, especially at the beginning of the coronavirus pandemic, was constantly turned on and that the patients heard and saw all the press releases and had the news broadcasts running in a loop. In this way, they sought information and knowledge about how to behave and they followed the infection rates with increasing concern:

> I've seen all the press conferences on the TV2 News [national TV channel] and I've been reading stuff on the lung association website and I've discussed these things with my aunt. In this way I have tried to work out what it's all about and what it means for me.

(ID 3)

Over time, however, several patients chose to shut down the news flow as the continuous focus on the horrors of the pandemic did not calm down, but rather disturbed the patients. Some made the rules for themselves that they only had to watch the press releases and a single newscast during the day, to avoid putting themselves in situations where anxiety and dyspnoea escalated:

> We just messed around at home here and talked about coronavirus all the time and saw all the news broadcasts. But then I thought I'd better stop watching all those news programmes because they simply made me feel worse.

> > (ID 9)

### 4.3 | To be "the forgotten"

The patients reported that they felt well taken care of when the Prime Minister closed down the country and on national television urged everyone to take good care of vulnerable groups of people in the community. They experienced that human life was put first and that all people, irrespective of social and health status, had value. A value that meant that life could not be measured in monetary terms. Unfortunately, patients also reported that this initial joy over the Prime Minister's and the health authorities' announcements faded as economic forces pressed for easing of restrictions and reopening the society. Patients found it difficult to witness the discussions about how many companies would go bankrupt to save a small number of patients from dying from COVID-19. During these discussions, patients experienced going from "being cared for" to becoming the down prioritised and "the forgotten":

> When the Prime Minister closed down the country, she said: 'The most important things for me are

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human life and the health of the population [rather than the economy]'. But she was only able to feel like that for a time because then the lockdown began to really hurt the economy and a lot of people lost their jobs. So in the end her priorities were suddenly reversed.

(ID7 + 8)

The experience of being "the forgotten" also arose in relation to the healthcare system. Without notice, rehabilitation therapy and group training facilities were shut down, annual routine check-ups and lung function tests were cancelled and scheduled examinations and treatments were postponed—sometimes indefinitely. In many cases, access to one's own doctor was also hampered by the situation with coronavirus. The patients experienced that some general practitioners would rather not see the COPD patients in the medical clinics. They feared that the patient should get infected in the waiting rooms or in contact with the staff:

> The doctor wouldn't see me [...] I just got a text message saying that my appointment was cancelled [...] the general practitioner was only dealing with lifethreatening conditions.

> > (ID 10)

Likewise, patients themselves were unsure whether it was safe to consult physicians and nurses during this uncertain period, which meant that some patients waited a long time before consulting a doctor with a health issue:

> I usually get an annual checkup at the doctors, but this year I haven't had one. I'd like to, but (sigh), those waiting rooms, you know, you can't be sure of anything can you? You just don't know who is sitting there do you?

I went to the doctor with some pains in my foot and they didn't even touch it. We just talked about my foot. That means I've been going around with a bad foot for five months without getting it examined.

(ID 3)

The majority of patients problematised the lack of information from healthcare professionals and they said that they wished they had been contacted, especially at the beginning of the coronavirus pandemic, to discuss worries, emerging issues and problems:

> I just could have used some more information, something that could reassure me. I know they [the health professionals] can't just be calling patients all the time, but I would have liked to have had a bit more contact, with the lung association, for example, or a

<sup>(</sup>ID 13)

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specialist department at the hospital, or something like that.

(ID 6)

I wish there was someone I could call if I had a question about something and could ask: 'So, when they [the Health Authority] say such and such, what am I supposed to do about it?

(ID 1)

A few patients reported that they have been in telephone or virtual contact with their doctor, a nurse or physiotherapist. For those who had, it was significant in terms of them feeling safe, comfortable and calm about the risk of being infected with coronavirus.

The closedown of rehabilitation therapy and limiting access to group training created concerns among the patients. They feared disability, loss of function and muscle mass. In addition, the patients missed the social interaction from joining group activities. One patient mentioned being instructed on home training and informed about the possibility of online training programmes. In general, the patients felt left alone with their worries, with a lack of training and rehabilitation.

The patients who received home care services worried about the risk of infection. Despite admonitions to care for the weakest in society, patients with COPD found that healthcare staff did not use protective equipment. They found it problematic that good distance was not maintained and that masks or visors were not used properly. The patients were afraid that the staff would carry coronavirus from home to home:

> ... they [home carers] come here and I know that they've been lots of other places, but they just go round in here and do the cleaning as they usually do. There's no difference.

> > (ID 13)

The patients felt that restrictions were taken lightly and that the health professionals 'forgot' that patients with COPD should be considered vulnerable to COVID-19.

### 4.4 | The uncertain future

The patients with COPD expressed uncertainty about the future. The prospect of a life like the one they knew about before coronavirus seemed far away. They did not believe that life would return to normal in the near future and some feared that they would not experience the world without a fear of COVID-19 in their lifetime:

> ... what I find is the worst thing is that there seems to be no end point. That's really frightening, because how long it's it going to go on? One year or 1 1/2 or two years?

Patients also expressed a hope for the development of a vaccine that could make everyday life back to normal, but they made no hopes that the vaccine was just around the corner. In turn, several expressed that they would take care of themselves, even if it meant a very long self-isolation period:

I'm staying where I am. Then I'll be doing that until I get vaccinated.

(ID 13)

I go around dreaming that the vaccine will come which can protect me [...] and the sooner it comes the better. (ID 2)

A few patients expressed that they did not have time to wait for the vaccine. Their lung disease was already so advanced that they did not expect to have many years of life left. They were so sorry to have to spend their last time in self-isolation that they were willing to risk their lives:

I can't cope with just waiting until the vaccine comes along, I don't want to do that. When it comes along I'll be dead.

(ID 10)

### 5 | DISCUSSION

#### 5.1 | Supporting hope

Our study shows that living with the risk of becoming infected with coronavirus was permeated with insecurity, sadness, loneliness and fear of death. Even though we do not yet know the full consequences of social and physical distancing for mental health (Holmes et al., 2020), the current study clearly showed how patient's mental well-being and everyday life is affected. Patients with COPD find themselves trapped in their own homes, which triggers worries and hopelessness. The patients expressed both feelings of hope and hopelessness. Hope was expressed in relation to the development of a vaccine, that could somehow bring their everyday life back to normal, but also the feeling of hopelessness was of existential significance. Not knowing how long the threat with coronavirus would last triggered deprivation and fear. The lack of physical contact with family, friends, lack of touching, hugs and kisses, as well as deprivation in relation to contact with professional health professionals, led to the feelings of loneliness and hopelessness. According to Yohannes (2021), frontline caregivers should actively engage in detecting the impact of COVID-19 on mental health. A recent study concludes that resilience and hope are protective factors in decreasing fear of COVID-19 and also in increasing happiness (Satici et al., 2020). Hope is an important concept that nurses have the potential to facilitate or sustain in others (Tutton et al., 2009). However, there is no way the nurse can help patients maintain hope and avoid hopelessness during

the corona pandemic if she is not available, accommodating, willing to talk to the patient and ready to act upon detected impacts on the patient's life, including mental well-being. A review by Brooks et al. (2020) investigated the psychological impact of being quarantined. The review showed that loss of usual routine and reduced social and physical contact often caused boredom, frustration, and a sense of isolation from the rest of the world. Even though the patients in the current study were not quarantined, but have chosen self-isolation, they may benefit from the suggestions given in the review such as health professionals focusing on reducing boredom, improving communication and giving adequate information (Brooks et al., 2020).

The patients with COPD reported that they increasingly used social media (Facebook, Messenger, Skype) to keeping contact with family and friends. This was considered the only way to interact in a 'corona friendly' way. The patients experienced that to some degree using social media could ease feelings of deprivation and anxiety, which also be seen in other studies (Brooke & Clark, 2020; Brooks et al., 2020; Xu et al., 2020).

## 5.2 | Warm distancing

Coronavirus has led to development of new models to avoid faceto-face contacts between health professionals and patients (Speth et al., 2020). Telephone and video consultations and internet-based interventions in education and physical training are rolled out as a substitute for physical attendance (Greenhalgh et al., 2020). These developments seem obvious solutions in order to maintain treatment, health promotion, disease prevention and rehabilitation interventions in the current situation as we face the coronavirus pandemic (Yohannes, 2021). In the present study, telephone calls were about giving advice on how to protect oneself against the coronavirus, or to postpone consultation appointments. The internet-based consultations aimed to facilitate timely transfer of patient-reported data, including physiological parameters, through a digital device. An interesting finding was that the patients who had received a phone call or a video-based consultation from a health professional felt very safe and were comfortable about the coronavirus situation. Internetbased consultations were mentioned by a few patients who were familiar with tele-healthcare consultations from before the coronavirus pandemic. Even though video consultations are already rolled out in many countries as part of national digital health strategy, we have seen challenges of scaling up this model at speed (Greenhalgh et al., 2020). After the coronavirus pandemic, we must expect an upscaling of virtual consultation. Another important finding was patients' disappointments with the healthcare system. The feeling of disappointment stemmed from the cancellation of long-term planned consultations involving lung function tests and about medical treatment. Cancellations were often made by digital post or a short message service without further explanation and with no prospect of a new consultation. The feeling of disappointment also arose when a health professional due to the health crises with coronavirus refused a need for a consultation. Refusals and cancelations of consultations

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contributed to a feeling of being left alone, forgotten and less important. Aside from handwashing and disinfection, social distancing is a significant preventative effort for reducing the spread of coronavirus. At the same, time social support plays a key role in most patient's well-being and mental health. Preliminary evidence suggests that symptoms of anxiety and depression and self-reported stress are common psychological reactions to the coronavirus pandemic (Rajkumar, 2020). A systematic review shows that implantation of tele-mental health programmes in psychotherapy is a promising and cost-effective method of increasing access to mental health services in the treatment of depression (Berryhill et al., 2019). Warm distancing to connect with patients with COPD can ease their symptoms, comfort them and give hope. Remotely delivering psychological interventions using a digital device is suggested to help patients during the current coronavirus pandemic. Health professionals play an important role in addressing these emotional outcomes as part of the coronavirus pandemic response (Pfefferbaum & North, 2020).

### 5.3 | Continued concerns

The first vaccine against COVID-19 was approved in December 2020, and the first vaccinations were carried out just before the end of 2020. Several vaccines have subsequently been approved and other pharmaceutical companies are on their way with new COVID-19 vaccines. Countries have developed various national strategies regarding vaccination programmes. The present study showed how patients with COPD hoped for normality as soon as vaccines became a reality. However, anxiety and worries about COVID-19 in the future have not disappeared with the wave of a magic wand. Although more and more people are being vaccinated, new challenges have arisen. New virus mutations have emerged. Mutations that patients (and societies) worry about, because as yet we do not know how they will develop, how contagious they are and whether they will reduce the effectiveness of the vaccines already developed. For patients with chronic lifethreatening diseases, such as COPD, this means that some patients will continue to isolate themselves and worry about the future and the risk of infection. Therefore, health professionals should continue to be focused on how to meet patients' needs for professional knowledge, for disease-specific and needs-identifying conversation as well as how to support the mental health of patients and their social contact with others - both virtually and physically.

#### 5.4 | Strengths and limitations

As researchers, we are responsible for choosing the research methodology best suited for the situation under analysis (Queirós et al., 2017). As the aim of our study was to produce in-depth knowledge in order to understand the existential significance of living with the risk of being infected with coronavirus in patients with COPD, we consider the qualitative methodology to be well chosen. Individual indepth interviews allowed us to uncover the patients' own thoughts 1728

and feelings about their everyday life during an extreme period with a worldwide coronavirus outbreak.

Despite ethical considerations in relation to conducting interviews with physical attendance, we chose to do so. Were it only possible to participate in the project virtually, we were worried that this might deter some patients from participating. For example, due to a lack of technical skills or old age. We are aware that by recruiting participants through Facebook, we may have excluded relevant participants from the very beginning of the project. However, we succeeded in recruiting participants with COPD of both sexes and with a wide variation in age and stages of the disease. Likewise, this form of recruitment was still possible at a time when it was difficult to reach out to patients, since, for example, medical practice, training facilities and centres for the older people were either closed or operated at reduced power.

According to Morse, to achieve data saturation, samples must be adequate and appropriate and the researchers must be skilled at interpreting data (Morse, 2015). In our study, patients were recruited from all regions of Denmark until data saturation was achieved. The findings in this study are based on interviews with 13 people who are all deeply affected by the situation coronavirus pandemic and COPD in everyday life. Data from several of the participants had essential characteristics in common, which according to Morse can be understood as replication (Morse, 2015). Both researchers are skilled in conducting qualitative research and have conducted numerous interview-based scientific studies in the past. We were guided by recognised methods and theories in both planning and conducting the interviews (Kvale & Brinkmann, 2015) and analysing the data material (Dreyer & Pedersen, 2009). We followed techniques that would help maintain the validity and reliability of interviewing, including avoiding leading questions, conducting a pilot interview and giving the participants the opportunity to clarify their answers and important message (Creswell, 2014; Kvale & Brinkmann, 2015). Quotes from the data material are included to provide credibility and to support the findings. The findings are specific to patients living with COPD but may be transferable to other groups of people, for example older people and patients living with another or multiple chronic life-threatening diseases. This research has thrown up many questions in need of further investigation. Further work needs to be done to explore how health professionals can meet the needs of patients with COPD during a threatening virus pandemic.

### 6 | CONCLUSION

This article contributes knowledge about the significance of living with the risk of being infected with coronavirus in patients with COPD. The patients feel compelled to self-isolate at home, as they fear dying if they are infected with the coronavirus. The patients feel great deprivation as a result of not being together with family and friends for a long period of time, without knowing exactly how long this period will last for. The insecurity and social distancing results in the feelings of loneliness, hopelessness and anxiety. The study shows that talking to and having regular contact with health professionals can calm and comfort the patient. The patients needed the coronavirus information and risk assessments from the news and social media to be 'translated' and explained by a health professional. This has not been common in Denmark during the first 6–7 months of the pandemic according to the results of this study.

## 7 | RELEVANCE TO CLINICAL PRACTICE

The findings of this study contribute to a broader understanding of COPD patients fear of coronavirus and the psychosocial consequences of shielding with self-isolation. Health professionals are in a strategic position to play a pivotal role in supporting patients when they are feeling anxious, lonely, hopeless, forgotten or lost. During a health crisis, such as a pandemic, the healthcare professionals can play a crucial role by being proactive in maintaining contact with the most vulnerable patients by regular telephone or virtual calls and consultations. The knowledge from the patients' perspective may be used to develop targeted interventions aiming adequate information, supporting hope and new strategies for implementation warm distancing contact to ease symptoms, provide comfort and hope.

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#### CONFLICT OF INTEREST

The authors declare no conflicts of interest with respect to the authorship and/or publication of this article.

#### AUTHOR CONTRIBUTIONS

Study design: CAM, DS. Data collection: CAM, DS. Data analysis: CAM, DS. Manuscript preparation: CAM, DS.

#### DATA AVAILABILITY STATEMENT

Research data are not shared.

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### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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