

ORIGINAL ARTICLE

Conceptions of everyday life among people living alone with chronic obstructive pulmonary disease

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ABSTRACT

Objective: The aim of the study was to describe conceptions of everyday life among people living alone with chronic obstructive pulmonary disease (COPD).

Background: COPD is a long-standing, chronic condition. As COPD progresses, it commonly affects all aspects of life. The disease creates a complex life situation for the person living alone, as they experience a wide range of difficulties and must adapt to the demands of their brittle body. They report more psychiatric distress than do those with other chronic diseases and appear to have an increased risk of depression. No previous studies have been conducted focusing on people's conceptions of everyday life when living alone with chronic obstructive pulmonary disease.

Methods: A phenomenographic study was conducted in the south of Sweden with 15 women and 9 men who were living alone and suffering from different grades of COPD, ranging from mild to very severe. Data were collected through semi-structured interviews.

Results: An overall descriptive category was found, when life changes direction, with three subcategories: COPD creates obstacles in daily life, when the body refuses and loneliness. The disease changed their lives dramatically and both physical and psychological strains appeared.

Conclusions: The present study highlights the particular challenges facing people living alone with COPD. To live alone and manage a chronic disease such as COPD is more problematic, than living with a spouse, as they have the option to ask for help when needed and someone to talk to. New technology can reduce social isolation among older people and may act as a potential solution for people living alone with COPD. Through e-health, these people may have the opportunity to be more involved in their own care. To ensure greater security, information, participation, self-care and independence, person-centred care must be systematically implemented within health and social care systems in Sweden.

Key Words: Chronic obstructive pulmonary disease, Everyday life, Conceptions, Phenomenography, Interviews

1. INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is an under-diagnosed life-threatening lung disease that affects approximately 600 million people worldwide. The disease is expected to be the third most common cause of death world-

wide in 2020.^[1] COPD is a non-reversible disease, and tobacco smoking is the main risk factor for developing COPD.^[2,3] People with COPD experience numerous symptoms such as shortness of breath, coughing, excessive mucus, wheezing, fatigue, frequent chest infections, pain, weight

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loss, muscle dysfunction, depression and anxiety. The severity of COPD is classified into four grades: mild, moderate, severe and very severe COPD.^[1] Studies indicate that smokers already in the mild stage of COPD exhibit increased mortality, increased hospitalizations, and decreased health related quality of life.^[4-6] Solano *et al.* revealed that palliative care is important for patients living with end-stage COPD.^[7] In addition there is often a financial burden when chronic disease affects a person in a family, which can lead to financial hardship.^[8-10]

People with COPD generally experience the diagnostic process as prolonged, and the diagnosis often creates uncertainty of what may happen in the future.^[11] Some days are described to be “good”, while other days can be “bad”; therefore, COPD is described as an uncontrolled disease.^[12] As COPD progresses, there is often a strong fear of suffocation and death, and the patients feel that death is constantly “on their heels”.^[13] The exacerbations increase as COPD progresses and are related to physical, social, and psychological impairments.^[1,14] Most frequent symptom is shortness of breath, often accompanied with increased mucus and coughing.^[15,16] Fatigue has both a physical and a mental impact and affects daily life significantly. The degree of fatigue worsens as the disease progresses.^[14,17-20] Patients with COPD report worse psychological functioning and more psychiatric distress compared with patients with many other chronic diseases.^[21,22] Prolonged illness such as COPD leads to changes in all aspects of a person’s life. A person’s self-care capability is reduced.^[1,13]

For people suffering from COPD who were smokers or ex-smokers, feelings of guilt and shame were common emotions; a type of self-accusation arose related to their smoking habits. These feelings were reinforced by other peoples’ attitude that COPD is a self-inflicted disease.^[13,23-25] They felt that they were exposed to stigmatized attitudes from not only society in general but also healthcare professionals.^[13]

Positive aspects can be present when a person is suffering from a chronic illness. Lower levels of symptoms cause less depressive symptoms, and if people’s bodies allow them to perform their normal activities, their physical and mental health-related quality of life is increased.^[26] Patients with COPD experience a wide range of burdens in their daily life and must adapt to the demands of their brittle body. Co-habiting adults affected by COPD are often highly dependent on their spouses/partners, especially when COPD progresses.^[13,23,27-29]

Currently, single households represent the most common form of habitation in Sweden. There are more than 4 million households in Sweden; 1.5 million of them are single

households, accounting for nearly 38% of all households.^[30] Previous studies have shown that people affected by COPD have difficulties coping and must handle their daily life without support from spouses and relatives.^[28,29] Therefore, it is important to explore how people living alone and suffering from COPD experience their daily lives and how health and social care services can best support these people. In Sweden, people with mild to severe COPD are usually managed in primary health care, while very severe COPD cases, especially if treated with oxygen therapy, are managed in hospital clinics.

Objective

The aim of the study was to describe conceptions of everyday life among people living alone with chronic obstructive pulmonary disease, classified according to different grades of the disease.

2. METHODS

A descriptive qualitative design with a phenomenographic approach was adopted to describe variations in single persons’ conceptions of daily life suffering from chronic obstructive pulmonary disease. Conceptions are essential in phenomenography and are based on variations in people’s awareness of the surrounding world.^[31,32] Phenomenography originates from educational research but has become a more common approach in medical and health care research. Phenomenography distinguishes between the first-order perspective, the actual state of something and the second-order perspective, *i.e.*, how a person conceives something or how something appears to them. Phenomenography describes conceptions using the second-order perspective, and are based on variations in people’s awareness of the surrounding world. The different ways in which a certain phenomenon is conceived are described in categories and sub categories, and the relationship between them is presented in Figure 1.

2.1 Participants

In line with the phenomenographic tradition, the participants were chosen strategically to guarantee variation in the data. The participants of the study were 15 women and 9 men, living alone and suffering from different grades of chronic obstructive pulmonary disease, ranging from mild to very severe. Twenty-four participants, aged 51-85 years (median 72 years), were included. They had lived alone for between 1 and 44 years (median 11 years) due to divorce (12 participants), and 12 were widows/widowers. The duration of COPD was between 1 and 25 years (median 7.5 years). Eight participants had COPD for less than five years, six participants for between 5-10 years and ten participants for over ten years. Four participants experienced mild COPD, eight mod-

erate, nine severe and three very severe. Three participants were still gainfully employed, five were in early retirement, and one of the participants was receiving 50% sickness benefit. Fifteen had reached retirement. Thirteen participants had stopped smoking four weeks to 15 years prior to the interview, and ten were smoking at the time of the interview. One participant had been a passive smoker for many years (see Table 1).

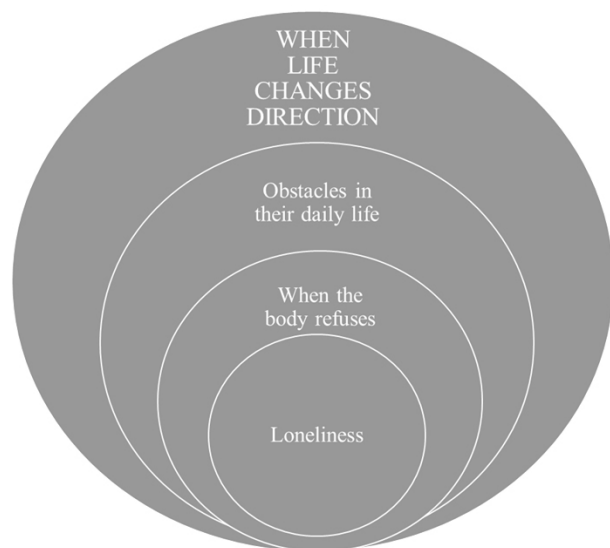


Figure 1. The outcome space
 One main descriptive category, “when life changes direction” with three subcategories: “obstacles in their daily life”, “when the body refuses” and “loneliness”

The study was conducted in the south of Sweden, and the participants were recruited from one hospital and different health care centres. The participants came from both urban and rural areas. Information was provided to health professionals to strive to recruit participants with differing grades and durations of COPD, ages and places of residence to maximize variation in conceptions.^[32]

2.2 Data collection

Data were collected between September 2013 and October 2014. Semi-structured interviews were used, which is the primary method for collecting data in phenomenography.^[32] An interview guide was created and tested. Two pilot interviews (included in the study) were conducted; because they functioned well, no further changes were made to the interview guide. The interview guide focused on the conceptions of people living alone with COPD. Examples of questions are as follows: “Can you tell me how it is to live with COPD in your daily life?”, “How do you perceive your situation as a single person having a chronic disease such as COPD?”,

“Can you tell me how it is to be cared for with COPD in the health care system?” This was followed by follow-up questions such as the following: “Do you have any strategies to make your everyday life easier, and if so, what are they? How do you perceive the response and support from staff?” In accordance with participants’ wishes, twenty-one interviews took place in the participants’ homes, one at a participant’s workplace, one in a quiet place at a café and another one at a university office. The first author, who had experience in the field, conducted all the interviews. Each interview lasted 40 to 110 min and with participants’ permission, was tape-recorded and transcribed verbatim by the first author.

Table 1. Demographic characteristics of participants

Variable	
Age (years)*	72 (51–85)
Gender (n)	
Male	9
Female	15
Duration of COPD (n)	7, 5 (1–25)
< 5 years (n)	8
5–10 years (n)	6
> 10 years (n)	10
Mild	4
Moderate	8
Severe	9
Very Severe	3
Marital status (n)	
Widow/Widower	12
Divorced	12
Years lived alone*	11 (1–44)
Gainfully employed (n)	3
Early retirement	5
50% sickness benefit	1
Retired	15
Smoker	10
Stopped smoking	13
Passive smoker	1

*Values are median (range)

2.3 Data analysis

Data were analysed using the principles of phenomenography described by Sjöström & Dahlgren.^[33] The procedure comprised seven steps (see Table 2) and is presented in an outcome space. The outcome space is shown in Figure 1. According to Marton,^[31] the outcome space is the logically structured complexity of different ways of experiencing an object acting as a synonym for the phenomenon of interest/study.

Table 2. Descriptions of the content of the seven different steps

Step	Content
Familiarization	Reading through the transcripts to become familiar with the data and correcting any errors in transcription.
Compilation	The most significant statements given by each participant were identified, and questions were asked about the text.
Condensation	Reducing longer statements to find the core of each dialogue.
Grouping/classification	Answers that appeared to have similarities were brought together.
Comparison	Selected statements were compared to find variations and establish categories that were distinct from each other and to revise the preliminary analysis.
Labelling	Each category was given an appropriate label to express the essence of the understanding of its content.
Contrasting	Comparing and contrasting the categories obtained to find the unique characteristics of each category.

2.4 Ethical considerations

Ethical approval was obtained from the regional ethics committee (ref: 2013/234-31). The study was conducted in accordance with the ethical standards of the Declaration of Helsinki (2013).^[34] The head physician and managers of the departments received written and oral information about the study and provided their written approval. When patients suffering from COPD visited the hospital or the health care centres, they received a letter of invitation from the nurse to join the study. The participants then sent a letter of consent to the first author. The participants provided their informed consent after receiving both oral and written information about the study. Participants could withdraw from the interview at any time without explanation.

3. RESULTS

An overall descriptive category was found, “when life changes direction”, with three subcategories: “COPD create obstacles in daily life”, “when the body refuses” and “loneliness”. The outcome space is illustrated in Figure 1.

3.1 When life changes direction

COPD affects everyday life in many different ways. Emotions of hopelessness and powerlessness arose when the patients felt a loss of personal control. When symptoms appeared, it changed people’s lives dramatically, especially if they lived alone, without support from a spouse. The consequences of physical and psychological strains appeared. Their lives became more altered than they had imagined, and they lived on a “one day at a time” basis. The participants had lived alone between 1 and 44 years, so they were familiar with taking care of themselves. After a while, they realized that it was very difficult to have COPD and to live alone and handle daily activities. Fatigue and breathing difficulties caused problems when they performed daily activities at home such as cleaning and shopping. Most of them had no one to ask for support; some had sons or daughters who could support them on occasion. Some participants found it difficult to ask for support because they were used to fend-

ing for themselves. The disease affected them differently depending on what grade of disease they had. COPD developed gradually, allowing them to adapt their lives thereafter. The feeling of being constantly reminded about the disease resulted in life seeming limited.

“The first hours in the morning, I am almost not able to do anything, and I decline from what I cannot do. The disease reminds you all the time, and I have to plan everything after the disease.” (10)

Things they could do previously were not as easy to do. Now, they depend on how they feel on that particular day. Depending on the progression of COPD, they needed to avoid doing more and more things in their daily lives, making them more and more dependent on others. To prevent breathlessness, they performed their tasks much more slowly than before, and they required rest from time to time. If they exceeded their bodies’ signals, they lost control of their bodies. They needed to economize their strength and wait for their ability to breathe. In those living alone, loneliness worsened the breathlessness and could lead to panic and anxiety.

To cope with their everyday life while living alone, they had to use different strategies. They were forced to plan their purchases and choose the most convenient shop and parking space, which were things that they did not have to think about before but now must because no one was there to do these things for them. They also needed to adapt their social life after developing COPD; as the disease progressed, their lives became increasingly isolated. They were alone in their homes, and they had difficulties meeting friends, especially when COPD was severe or very severe.

“That’s life, I have to learn to live with this, I have to try and not put myself in situations, but it’s very hard because I’m so involved, and then it is difficult to dampen down. It’s tricky, and I know that it is only one aspect of this.” (23)

3.2 Obstacles in their daily life

They could no longer do things that had previously been an important part of life. They experienced fear of the future

and of the development of COPD, and they were uncertain about how and when the disease would progress and how they would manage their situation, as they were living alone without support. One of the obstacles was related to the housing sector, the difficulty in obtaining another accommodation that would facilitate their new situation. To continue living in their own homes involved the requirement that the dwelling was adapted to their needs and circumstances. Some of the participants were living in their own houses, and some were living in flats. Some experienced difficulties because the accommodation was too expensive for them; this issue emerged especially when they had been widowed. There were participants who had been on waiting lists for a new apartment for many years. Several feared getting an apartment in another municipal district, and if they refused the offer, they risked being placed last in the queue. Some of the participant faced financial difficulties, especially the women, and they only had their own pension. which was low for some participants.

“I cannot afford to live in the house because of my poor pension. I’ve been waiting for an apartment for several years, I asked if they had immediately available apartments, but it could take a couple of years. If you stand in line and get an apartment in another part of the municipality, you have to say yes. What can I do then if I don’t know anyone there?” (1)

Some participants’ had home care; the negative side was that the support was minimal and insufficient in some cases, with five minutes of care in the morning and five in the evening. Their experience was that they were not provided support; instead, they were provided one action. They felt that no one asked for their statements and desires. There is no time for home care staff to sit down and talk, and it is exactly calculated how long they can stay until they must go to the next care receiver. As COPD progresses, they become more and more dependent on help from others, especially if they are single, as they have no spouse to help them.

“The girls in the home care service were wonderful and helpful. The downside was that it was 5 minutes in the morning and 5 minutes in the evening, and the cleaning was also less than an hour. That is the downside, you get no support. You get one arrangement, you get the insulin, and they help with one of the socks.” (7)

It became increasingly difficult to travel further away from home, and they were afraid to travel on their own. Both the disease itself and the progression of the disease put an end to long journeys, such as trips abroad, and the economy also played a role. As single persons, they did not have the same economic opportunities as couples. Some of the participants had difficulties getting away from home at all, which

restricted their social life tremendously. They often used the store that was close to their home; the walker was a tool that allowed them to do some shopping and wandering around in the surroundings. If they owned a car, they used to park it close to their home and take one bag at a time. To live alone, they were forced to plan their actions, for example, food shopping, as they had to carry their own bags themselves. It was difficult to carry heavy things, so they needed to divide the food into two bags. Sometimes, they were forced to ask for support with shopping when they were too affected by COPD symptoms.

“I’ll shop sometimes, and sometimes I get help. Pushing the shopping cart is ok, but it’s tough when you have to carry the food home. Sometimes you have to stop and catch your breath so do you don’t panic.” (14)

Thirteen participants stopped smoking when they received their diagnosis or sometime after. Ten continued to smoke, and one had been passive smoker. Several expressed that it provided them inner peace, a sort of consolation. Participants’ senses of loneliness were one of the reasons they gave as to why they continued smoking. Many experienced isolation because of their COPD, and their smoking habits provided them comfort. If they were feeling emotionally fragile, they expressed that they found it even more challenging to quit smoking. They considered that the decision to quit smoking must be theirs and no one else’s. Some found that others nagged them to stop smoking; such nagging was justified, but it began as soon as they walked through the healthcare doors. This resulted in that patients’ not accepting the information about the drawbacks of smoking.

“I have been told by healthcare officials so many times that I should stop smoking, I can take advice, but when someone says do it, it is not worthwhile, I have to do it myself.” (15)

Some participants saw the cigarette as a companion in their solitude. Psychological reasons for smoking played a significant role in continuing to smoke. The smoking placed them in a comfort zone because it increased their well-being and self-esteem in their loneliness. The smoking could also reduce their negative thoughts; for some, smoking was their friend and companion in their loneliness. Other participants felt that it was not worth it to stop smoking because no one else cared; thus, smoking was a solace for them.

“Some days, when I feel good, I smoke only 3-4 cigarettes. Some days, when I feel bad mentally, and I wonder and think, then maybe it will be 7-8 cigarettes, then I do not stop. I can see that smoking is a consolation.” (3)

Some felt that it did not matter if they continued to smoke, as they had smoked so many years. Thus, instead of bringing a

fight against the smoking, they wanted to enjoy old age and their cigarettes. Smoking could also represent a type of defiance. Some of the participants had been told by their doctor that if they continued to smoke, they could blame themselves and therefore could not get any help from healthcare.

“Healthcare cannot see outside the box; they only see that it is smoking. They are concentrating too much on one thing; they are narrow-minded.” (14)

Several of the participants experienced no involvement in their care. As their experience was that the COPD diagnosis was associated with smoking, it became an obstacle to be involved in their own care. Some of the participants were not always met with understanding from the healthcare system if they had not managed to stop smoking.

Healthcare personnel did not consider the whole patient and his/her life situation. They only discussed what medications were needed and did not ask how the COPD sufferers managed their situation at home. The healthcare provider overlooked and did not at all emphasize that the patient was single with no possibility of support at home. Some of the participants felt that it was difficult to question different medications and make suggestions. Uncertainty and insecurity arose when the participants needed to meet different doctors.

“The doctor does not relate to the situation that you’re in. If a person lives in a relationship, they have a backup, someone to communicate with, but the doctors don’t talk about this at all.” (14)

In contrast, some of the participants felt involved in their care, they felt cared for and safe. They felt that they were treated well by the staff. Several participants expressed that contact with healthcare professionals provided them a sense of security. Some participants described that the staff were their only source of safety. They felt that the staff had gotten to know them, that they cared about them, and that they did everything for them. The physician and, above all, the COPD nurse provide stable security. Positive feelings were experienced when staff saw the person behind the COPD diagnosis, with their pros and cons. They were satisfied when they felt support, affirmation and a sense of connection, and they were not alone in their illness because someone cared for them.

“The only security I have is the COPD nurse at the health centre; she is a wonderful person.” (13)

Some argued that what is lacking in COPD care is psychosocial support from healthcare professionals. Most of the focus is on the physical body, the lungs and symptoms, and very often they overlook the mental part. Their psychological well-being was affected, especially when they noticed changes

in the body due to disease progression. Feelings of anxiety and thoughts of death were not unusual, and they needed someone to talk to about their feelings; this was very notable with the people living alone. A caring meeting involved the staff meeting the whole person, considering their body, mind and spirit. The holistic mind-set was missing.

“The mental part, no one bother with it; there is no holistic thinking in medicine and medical treatment; we play on different halves.” (23)

There was some concern about the risk of infection while staying in crowds. Most of the participants had experienced several cases of pneumonia; some of them had been admitted to hospital. Colds, snotty grandchildren, and infected colleagues created vast problems for them, especially work colleagues. Someone needed to change their work duties because they could not work in smoky environments or among people. For those participants who were more isolated, they had a lesser risk of infections, as they were not with other people as much.

“I went a roundabout way when I heard someone coughing. I was always so sick, so I was hospitalized. Now I’m sitting alone in an office, where I sit the whole day until I go home. You get a little more alone.” (21)

Some of the participants felt that the care they received only consisted of the prescription of medicine. The high-cost ceiling for medication and medical visits was a great support. Several participants had marginal economic resources, while other participants had good economic resources. Some of the participants stated that they had not been able to obtain their medication unless the high-cost support was available. Someone could not purchase some of their medicine because it was too expensive. They only had their own pension, which was low according to some participants; that was the only income in the household.

“Healthcare and care... you don’t receive any care. They just give you a shitload of pills, and otherwise you get no help. Now I have heart medicine and one of those inhalers. It’s so damn expensive that I cannot afford to obtain medicine.” (5)

They understood and had experienced that they could not forget their medicine; otherwise, they would be directly reminded. This resulted in that they had to plan more and have their medicine everywhere, such as in purses, in desk drawers and beside the computer. This was more significant for people with COPD living alone, as they have no-one living with them to regularly remind them to take their medicine.

“I always have the medication with me. Everything stops around me, I get scared and have cold sweat.” (7)

Some of the participants felt restricted because they had to take their medicine every four hours in the inhalation device. Some experience difficulty walking in shops and especially in large shopping centres. Knowing that it was far to the exits could easily create panic anxiety, and they were often walking alone and had to rely on themselves. Different scents in stores could cause problems; if so, they needed to go out of the shop and medicate. They had feelings that no one could take care of them if something were to happen to them.

“I panic, I know I cannot get out as fast as I want. You become more afraid. You may be afraid that you will not make it home in the four hours between inhalations. If you have no control, you begins to hyperventilate, and anguish comes. It will be stressful, you need to plan.” (4)

Several participants had not received any information about what COPD was and what it meant for their daily life and the future. Some had received a folder to read. Ten participants had been offered and attended COPD school. Thirteen participants had not heard about or been offered OPD school. One participant has been offered but declined to participate. No knowledge of what COPD is increased feelings of insecurity, and this was noticeable when they lived alone because they needed someone to talk to and ask questions to.

“You know terribly little about the disease itself. I got a folder about COPD from a nurse.” (3)

“It’s only a nurse who has told you that you should not smoke, it’s the only thing I know.” (12)

3.3 When the body refuses

The participants’ relationships with their own bodies changed when COPD progressed; they did not recognize their own bodies. In the end, symptoms and bodily changes could not be ignored, and they felt that their situation became more difficult when living alone. There was a concern about how they could manage their situation and remain living in their own homes by themselves. They learned to listen to their body signals and not ignore them; if they did ignore these signals, it caused many difficulties, including breathing difficulties. Participants felt that when shortness of breath and feelings of concern arose, daily activities that were previously managed could no longer be conducted. This was a major concern. The body could not cope with stress, they had to take everything slowly, and what was not done that day had to wait until the next day. Some participants had a fear of their symptoms becoming so poor that they would require oxygen therapy, making living alone more difficult.

“I cannot be out and walk because I get very breathless, I have not been out in 1½ years. If I should vacuum or do anything else, I need to take it little by little because I have

no strength and get out of breath.” (1)

The feeling of being constantly reminded about the disease led to existential pain. The disease affects their daily functional ability; their body speaks out very clearly and governs their activities, and they must follow. The body provided signals directly if they forgot to take their medication, and they had no one to remind them. They felt that the symptoms affected their ability to engage in activities, and this reduced their opportunities to meet other people. Some days, the participants did not have enough energy, which complicated their living alone situation. The further the illness progressed in severity, the harder it was to manage the home situation. COPD limited the lives not only physically but also psychologically to a great extent. The body that previously worked could no longer be trusted, and concerns about the future and how they could cope and remain living alone in their home.

“If I do not have to go upwards, I go at my pace, and it is fine. When I go shopping, I usually divide it in two bags, and if it is too much, I’ll take the car. Otherwise, it will be difficult to breathe. What I do not have time to do today, I do tomorrow. You learn how to make up for things.” (2)

Some participants had to hold back on certain things in the home, such as cleaning; if they owned a garden, they did not have the strength to deal with it. Some of the participants received support from home help staff, and others thought it was too expensive and did not receive the support they really needed, such as with window cleaning and whip carpets. This made it difficult for those living alone because they needed support. Some hired help from private operators, such as for window cleaning. Most of the participants did not ask for help from neighbours or friends. Someone had asked for help to be chauffeured to the doctor for an emergency visit. Two of the participants had asked the neighbours for window cleaning and some indoors cleaning, which they paid for.

“When the home help staff comes, I have to take away all carpets because they don’t do that work; therefore, I have been feeling a little poor today because I have been involved with moving the carpets. You must not rush, and stress is the worst thing you can do.” (3)

Shortness of breath created anxiety and panic, which in turn exacerbated the symptom and further increased the anxiety and panic. The loneliness caused panic, and the breathlessness worsened; this became very clear when people were living alone. There was a fear that they could die without anyone knowing about it, and they felt that they were left alone with their panic, general anxiety and death-related anxiety. Several of the participants did not know how they would

be able to move forward in life with their disease.

“It’s tough. You feel panic and anxiety, but I have medicine. I woke up at night with the fear of death and did not dare go back to sleep; it’s my whole situation, how to move on, and I realize that I have to cut down on smoking, but in some situations, I do not care.” (1)

Taking a shower could pose difficulties; the moist air and hot water could be good in some cases, but it could also cause panic. It was difficult for the participants to lift their arms because it caused breathlessness.

As COPD cannot be seen externally, it could sometimes lead to discomfort in the form of glances from other people. Sometimes, when participants were out walking with their walker and became breathless and dizzy, they were thought to be intoxicated.

“It’s really tough when you are out and lose your breath and panic because then people think you have drunk, and then you get these disparaging glances.” (3)

3.4 Loneliness

There was variation in how lonely and isolated the participants felt depending on the progression of COPD. In grade 1, mild COPD, there was no impact on their social lives. This changed as COPD progressed; they needed to account for their symptoms more and plan their day accordingly. Although they previously had a large social network, they could not maintain this as their condition worsened; the worse the disease, the harder it was to maintain activities and friends. In the end, they became isolated, especially if they did not have any relatives in close proximity. As single and chronically ill people, they experienced loneliness as the worst effect.

“I think that loneliness is the biggest problem - that there is no one who cares about me and no one to see me, considering whether one is lying on the floor and did not get any help, it is clearly worrisome then.” (9)

Several participants argued that it would have been easier to be part of a couple because then you can get help from the spouse and have someone to share the chores. They lack having someone to talk to and someone who listens to them. As a single person, one is responsible for doing all the chores without support.

“Smoking is a comfort, especially now that I am alone and sit and stare at the walls; then, it’s tough.” (16)

Activities were limited, and they reduced the number of trips, even of those in the immediate area, gradually with the dis-

ease. This resulted in feeling that they were imprisoned in their homes. They were forced to set limits to what they could cope with. It became difficult to keep up with friends on outings or shopping. Due to this, they experienced grief, anxiety and feelings of losses in their lives.

“I feel isolated, I do, and I have to set boundaries for myself. I cannot go to the mountains and ski anymore, I cannot go on holiday to the Canary Islands as I want. You are imprisoned, you get to see the good that has been.” (3)

If they did not have close relatives near them, some of the participants tried to build a safety net of neighbours who could help when needed. The participants did not want to intrude on their neighbours too often; they just wanted to be neighbours. Some of the participants had lost their contacts, and some did not know their neighbours at all. Having a neighbouring contact was not ubiquitous. Some experienced that the evenings were easier because they could watch TV, and the feelings of loneliness decreased. The worst experience was when they went to bed for the night or if they awoke during the night due to loneliness, memories and COPD. They experienced the regret of not having any adult to communicate with; often, the cigarettes became a consolation.

“When you do not have an adult to communicate with when you feel that it does not matter, I’ll take a cigarette, it will be a friend.” (14)

Social situations were also avoided because of the fear of infection; they knew that this would be a risk of obtaining lung infections and exacerbating their COPD. This was not always easy to handle, especially not when it came to being in contact with grandchildren.

“I always tell them that if they are really having a cold then say to me, it happened to me that I come there and they’ve been through a cold. When I’m bad, then I feel this loneliness even more.” (8)

The fear of not getting enough air was something participants experienced daily when their COPD was more advanced, and the thought of being suffocated to death and being alone created anxiety. There was a concern and fear of death, and much of their fear was that they were afraid to be left alone at home without anyone asking for them. There were also concerns on how their death would be and they were frightened enough to be tormented; they did not want to end up as a parcel.

“Sometimes I think about it, if I would lie down and die on the sofa before someone was going to call.” (22)

4. DISCUSSION

4.1 Discussion of the results

An overall descriptive category was found, “when life changes direction” with three subcategories: (1) COPD creates obstacles in daily life, (2) when the body refuses, and (3) loneliness. To the best of our knowledge, this is the first study describing people’s conceptions of everyday life when living alone with COPD, according to different grades of the disease.

The disease affected them differently depending on what grade of disease they had, but their daily lives were already affected by grade II COPD. A chronic disease such as COPD can quickly become acute, and the person will require hospital treatment. There are heavy demands on people living alone to cope with, and they must read the body signals when acute events occur. The difficulty is that the ill person has no close living person who can support them when an emergency occurs and when they are released from hospital care. Previous studies show that health care personnel largely trust that relatives will care for the ill person, and the relatives also feel a duty to do so.^[28,29,35] Care from healthcare professionals for a person who lives alone with a progressive disease such as COPD involves special challenges. Healthcare professionals should capture the needs of each individual patient and strive to understand the individual’s experience, expectations, needs for psychosocial support and other needs to have a good quality of life when they come home. This is especially of great importance when the patient lives alone and has no support at home.

It is important that each patient is seen as an individual rather than as a diagnosis. Healthcare professionals should focus on the patient’s needs and resources for the future, and the patients themselves should be involved in the care process. If healthcare professionals strengthen patients’ empowerment, the patients living alone will be capable of identifying and dealing with their problems when they are in their homes. In person-centred care, the patient is involved in their own care planning; this type of care is based on a partnership between the patient and the healthcare professionals, with the patient’s story always being the starting point.^[36,37] This provides the healthcare professionals with insight into the patient’s daily life and into the difficulties that the patient may face while living alone and the possibility to provide the support that the patient asks for. It is important that healthcare professionals know and understand the life that the person live in their home to ensure that they can manage on their own or to determine if there is something that will worsen their disease. For example, why do many people continue to smoke despite their COPD and severe symptoms? The

present study shows that ten participants were still smoking. It also shows that participants’ sense of loneliness was one of the reasons that they could not stop smoking. They experienced isolation because of their COPD, and their smoking habits comforted them. If they were not mentally balanced, it was even more difficult to quit smoking. As shown in a previous study, the psychological factor plays a major role in the ability to quit smoking.^[13] Many people continue to smoke to enhance their feelings of security, well-being and self-esteem and to reduce their negative emotional state and anxiety.^[13] Psychological support should be integrated into the care plan. The contact with the health system should not induce feelings of guilt, shame and stigmatization within the patient. Previous studies show that patients with COPD can occasionally be exposed to stigmatizing attitudes from both society and within the healthcare system.^[13,23–25]

Old people appreciate having their own housing, despite being sick and in need of support from others.^[38,39] A previous study shows that even if they live in a retirement home, more than half of the elderly experience loneliness.^[40] The housing sector was one of the obstacles that arose because of difficulties finding new accommodations. There is a housing shortage in both private rental property and co-operative housing as well as bed shortages in nursing homes. For some, maintaining their accommodations was too expensive after becoming a widow or widower; their pension was not enough. The opportunities to move to better and more adapted housing in time were dependent on how much they could pay as well as on the availability of good and accessible housing. A Swedish Pensions Agency report^[41] highlighted that in Sweden, every other woman who retires today falls under the EU’s definition of the poverty line in Sweden, receiving a pension of 10,800 per month before taxes. The financial situation was not the only difficulty; the queuing system creates problems because they may receive an accommodation far from their familiar environment, which would also increase their isolation. If they say no to the accommodation, they are placed last in the queue. There was a concern about being totally isolated in a new area where they did not know anyone.

Several participants in the study have marginal economic resources, especially the women, and the high-cost ceiling for medication and medical visits supported them to a great extent. Studies have shown that when chronic disease affects a person in the family, it can lead to financial hardship.^[8,9] There is a lack of studies showing how this financial hardship affects chronically ill people who live alone; therefore, further studies are needed. According to the Social Services Act,^[42] the Social Welfare Board should ensure that old people with a chronic illness are able to live independently in

safe conditions and have an active and meaningful existence. All efforts should be based on an individual assessment, which should respect people's sovereignty and integrity.

Healthcare is required to provide the patient information on his health status, care and treatment that is tailored to each individual. Out of twenty-four participants, only eleven were offered COPD School, one of whom declined to participate. Thus, thirteen participants had not heard about or been offered COPD School. COPD School led by a nurse should be obligatory to provide to each patient afflicted with COPD. Wong^[43] found that patients' knowledge about COPD was poor, and they were not confident with self-management. Nurse-led COPD School in cooperation with the patient to support them and educate them about their disease should be even more important for persons living alone to provide them with a chance to handle and to improve their situation. Healthcare professionals should actively address the individual and social settings of persons with COPD to ensure person-centred care is provided.^[36,37] Healthcare professionals must understand each patient's situation and develop interactions and participate in a manner that reaches beyond the healthcare walls. People living alone with a chronic disease spend most of their time at home; by seeing the people, the person-centred care could also be accessed in their own home, where the patients spend the vast majority of their time.

Carnevali^[44] describes how daily life and functional health status coalesce with each other. The model is based on interpreting internal and external patient resources and on how well the balance exists among everyday life, functional capabilities and the internal and external resources available to meet these requirements. In the best case, the patient meets with their doctor once a year and with their COPD nurse more than once. A prerequisite for mental health is to know the meaning and context of life. In the present study, several participants described anxiety and depression as a frequent part of their lives. Living alone and being sick, they need more support than occasional visits to health care; they require support from internal and external resources. According to Carnevali, the internal resources are allocated as strength, endurance, sensations, mind, knowledge, motivation, courage, skills and communication. These resources indicate, among other things, the motivation to perform self-care and to acquire knowledge about their disease and treatment. The external resources are described as all resources that are outside the person themselves. It is important that professionals ensure that the patients have internal and external resources, especially when they have COPD and live alone. When the person does not have sufficient capacity to take on the demands of daily life, they are in need of external resources

such as adequate housing, other people, pets, technical aids, communication facilities and transportation facilities. With this background, it is important for healthcare professionals to identify which internal and external resources the patient has, especially with a patient who is living alone, according to person-centred care.^[36,37]

The present study shows that persons living alone and suffering from COPD had restricted lives; depending on the progression of COPD, their lives gradually deteriorate, and they become more and more dependent on support. Due to an increasing population of ageing people struggling with chronic diseases such as COPD, the European healthcare system is confronted with different concerns and challenges. New technologies have been shown to help reduce social isolation among older people; this could be a potential solution for people with COPD living alone. There is growing evidence of the value of technologies such as telecare, telemedicine and telehealth to support older people with both physical and mental long-term conditions and to relieve carers.^[45-52] A study shows that the feelings of safety, security and availability are increasing among patients who are part of the "telecare" system.^[53]

E-health services result in an increased opportunity to stay and be cared for at home when COPD progresses. Through e-health in the home, patients are more involved in their care, and they have the opportunity to develop a sense of comprehensibility, manageability and meaningfulness. The support the persons receive through e-health services results in increased control and an increased ability to manage their disease.^[51,52,54,55] There may be a risk that the ill and elderly experience difficulties with the new technology, according to Finch.^[56] Other studies found that responders find e-health easy to use and to learn, but people with less education and no prior experience with the internet require more education.^[57,58] Health professionals and, above all, nurses involvement in e-health is crucial.^[59] According to two surveys^[60,61] of newly qualified nurses and program managers at nursing schools in Sweden, newly graduated nurses do not feel that they have sufficient knowledge of e-health from their basic education. COPD is one of the most prevalent diseases worldwide;^[1] therefore, Europe will face major challenges due to COPD. The availability of e-health and contact with healthcare professionals allows the patient to feel more empowered and to increase their participation; additionally, they can create a sense of coherence of their situation, and they have the opportunity to stay home even if they live alone. An increased effort should be made in nursing education to introduce teaching about e-health to meet the demands of the increasing elderly population, the increasing number of people with chronic diseases such as COPD and the continu-

ously growing healthcare costs. Further research is required to investigate the support of e-health by healthcare professionals and COPD sufferers who are living alone and if the patients' internal and external recourses are enhanced by the tool.

4.2 Methodological discussion

The focus of the study was to increase the knowledge and understanding of people's conceptions of everyday life when living alone with COPD of different grades. The authors have critical considerations regarding the contents of the conceptions and the descriptive categories in terms of trusting the entire analysis process.^[62] Semi-structured interviews were chosen to achieve a deeper awareness and understanding in a field in which knowledge was lacking. This is a recommended method for collecting data in phenomenography. The interview guide guaranteed that the same questions were posed to all participants. Several considerations were made to increase the trustworthiness of the study. To enable transparency of the analysis, quotes from the interviews are accessible to provide the reader with an opportunity to evaluate the interpretation as well as its relevance to similar settings. A strength is that twenty-four interviews were conducted, which is considered an adequate number to allow for different conceptions.^[31,32] Another strength was that the participants came both from urban and rural areas. The data can be transferred to other settings in Sweden and probably to other countries with the same health and social care system. The interviews were conducted at one point in time; a longitudinal approach, where successive interviews are conducted over time, would help to more fully understand the illness trajectory of people with COPD living alone. Another

strength of the study was that the participants were given the opportunity to describe their conceptions of daily life.

5. CONCLUSIONS

The present study highlights the everyday challenges facing people living alone with COPD. It is more problematic to be a person living alone and managing a chronic disease such as COPD than it is to be a person living with a spouse, as they have the option to ask for help when needed. COPD changes the future and create consequences of physical and psychological strain. Their experience of loneliness and isolation was the worst thing that they had to manage. The starting point in healthcare should always be the patient's story, which allows for person-centred care. Person-centred care is based on partnership, and the focus is on the person's needs and resources, which are very important for all people but especially for people living alone with a chronic disease. Although COPD is considered a system-specific disease, it causes many mental health problems, as well; therefore, psychological support should be integrated into the care plan. Through e-health, the person living alone with COPD could be more involved in their care. The e-health service could provide the COPD sufferer living alone with the appropriate information, education and support to practice self-care and increase their quality of daily life.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare that they have no conflict of interest.

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