

Unlocking the limitations: Living with chronic obstructive pulmonary disease and receiving care through telemedicine—A phenomenological study

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Aims and objectives: To describe the lived experiences of quality of life among a group of patients living with chronic obstructive pulmonary disease who were included in a telemedical intervention after hospitalisation for disease exacerbation.

Background: Patients with chronic obstructive pulmonary disease have high symptom burden, poor control of symptoms and a need for greater requirements in care. Telemedicine can provide benefits for patients with chronic obstructive pulmonary disease by improving self-management.

Design: Descriptive phenomenological approach.

Methods: Ten in-depth interviews were conducted with chronic obstructive pulmonary disease patients participating in a telemedical intervention. The collected data were analysed using a descriptive phenomenological research method.

Results: Living with chronic obstructive pulmonary disease was experienced as creating physical and mental limitations of the diseased body and an increasing identity as a patient, which led to impaired quality of life. Being included in the telemedicine intervention increased accessibility to healthcare services and support from telemedicine nurses. Self-measurement of health data increased participants' clinical insight and created a mutual clinical language in dialogue with telemedicine nurses, which led to increased quality of life. However, receiving care through telemedicine was also experienced as a dual chore.

Conclusions: Telemedicine can reduce the perceived limitations imposed by chronic obstructive pulmonary disease through four key elements: (i) improving accessibility to healthcare services, (ii) increasing support from health professionals, (iii) strengthening clinical insight and (iv) developing a mutual clinical language, thus increasing quality of life. The transparency facilitated through telemedicine in this healthcare context encourages open decision-making, where the participants can increase their knowledge and improve acknowledgement of and collaboration with telemedicine nurses.

Relevance to clinical practice: Telemedicine can be beneficial when rethinking care for chronic obstructive pulmonary disease by providing knowledge on how living with chronic obstructive pulmonary disease can affect the experience of

receiving care through telemedicine and further determine for whom telemedicine is useful.

KEYWORDS

chronic obstructive pulmonary disease, nursing, patient experience, phenomenology, quality of life, self-management, telemedicine

1 | INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a serious and progressive disease representing a significant burden on both patients and healthcare systems (Vestbo et al., 2013; WHO 2016). Living with COPD is related to both physical and emotional limitations. Having a severe degree of COPD implies a high symptom burden (Gardiner et al., 2009; Simpson & Rocker, 2008), entailing continuous changes that have a considerable impact on a person's quality of life (Ek & Ternstedt, 2008; Frasier, Kee, & Minick, 2006; Simpson & Rocker, 2008; WHO 2016). The breathlessness is particularly difficult to endure and contributes to the greatest restrictions in daily life (Blinderman, Homel, Billings, Tennstedt, & Portenoy, 2009; Ek & Ternstedt, 2008); therefore, the high symptom burden of COPD is often followed by poor control of symptoms (Gardiner et al., 2009).

Chronic obstructive pulmonary disease is increasingly common, and according to the World Health Organization, COPD will rise from the sixth to the third most common disease worldwide by 2030 (WHO 2016). Due to this increasing prevalence, there is a need for more focus on prevention and treatment (Simpson & Rocker, 2008) and requirements for care (Gardiner et al., 2009). Following up patients using telemedicine (TM) has shown promising results for patients suffering from COPD (Gale & Sultan, 2013; Gorst, Coates, & Armitage, 2016; Vatnøy, Thygesen, & Dale, 2016; Williams, Price, Maxine, Tarasenko, & Farmer, 2014). TM can be defined as "information, communication, and monitoring technologies which allow healthcare providers to remotely evaluate health status, give educational intervention, or deliver health and social care to patients in their homes" (Solli, Bjørk, Hvalvik, & Hellesø, 2012, p. 2813).

2 | BACKGROUND

The use of TM in healthcare services has increased significantly the last 20 years (Wotton, 2012). Although follow-up of patients with COPD using TM has shown promising results, there is still ambiguity with regard to efficiency (Cruz, Brooks, & Marques, 2014; Pedone & Lelli, 2015; Wotton, 2012). The uncertainty pertains particularly to the effects of hospital admissions and mortality (Kamei, Yamamoto, Kajii, Nakayama, & Kawakami, 2012; McLean et al., 2012) and to the effect on quality of life (Gregersen et al., 2016; McLean et al., 2012). However, as TM is expected to play a greater role in future global

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

- Increased in-depth understanding of care needs for patients with chronic obstructive pulmonary disease (COPD) by performing descriptive phenomenological research.
- Insight into how living with COPD can affect the experience of receiving care through telemedicine (TM) and to further determine for whom TM is useful.
- Telemedicine promotes transparency in healthcare services enabling open decision-making that can improve acknowledgement of and collaboration with healthcare professionals.

healthcare delivery, it will be increasingly important to develop a strong and diverse evidence base (Dinesen et al., 2016).

Living with COPD represents a significant challenge, and to manage the condition and high symptom burden, there is a need for continuity of care, regular follow-up, and support from healthcare professionals (Gardiner et al., 2009; Pols, 2006), with a focus on achieving self-management (Lawn, Delaney, Sweet, Battersby, & Skinner, 2013; Vatnøy et al., 2016) to further increase quality of life. Qualitative research has shown that TM has the potential to increase quality of life by giving increased access to healthcare services, which facilitates collaboration with healthcare professionals (Mair & Whitten, 2000) and access to information (Williams et al., 2014). In addition, TM strengthens self-management through self-monitoring (Horton, 2008; Vatnøy et al., 2016), by contributing to a better understanding of the condition (Gorst et al., 2016).

The use of TM represents an intervention in the patient's daily life and changes the way the patient relates to healthcare services. Therefore, more studies are needed to gain precise knowledge about the patient's lived experience related to the use of TM equipment (Emme et al., 2013; Greenhalgh et al., 2013; Ure et al., 2012) and to learn about what matters to the user of TM technology (Greenhalgh, Procter, Sugarhood, Hinder, & Rouncefield, 2015; Greenhalgh et al., 2013). Because people with COPD live with symptoms that present a significant burden in daily life, it is particularly important to have knowledge of how TM affects their life situation. Based on phenomenological philosophy, this study obtained knowledge on the individuals' lived experiences of living with COPD when receiving care through TM.

3 | METHODS

The aim of this study was to describe the lived experiences of quality of life among a group of patients living with COPD who were included in a telemedical intervention after hospitalisation for disease exacerbation.

3.1 | Design

This study consists of a descriptive phenomenological research approach and is based on the narratives of lived experiences of quality of life among patients living with COPD that have been included in a telemedical intervention. Phenomenology is the study of structures in a phenomenon, as they appear in our consciousness. The philosophy of phenomenology goes back to the early twentieth century. Edmund Husserl founded the philosophical thinking of modern phenomenology, stating that a phenomenon exists in people's mind and thus can only be explained based on the perspective of those who have experienced it. Based on this notion, researchers have to set their own pre-understanding in brackets in order to reach an unprejudiced description of the person's experience of the phenomenon (Giorgi, 2009).

3.2 | Intervention

The study was part of a larger European project "United4Health," carried out in southern Norway that explored a TM intervention monitoring patients diagnosed with COPD (European Commission 2015, Smaradottir, Gerdes, & Martinez, 2015). When discharged from the hospital, the patients received TM equipment for usage at home. The technical equipment consisted of a tablet with video camera, and a pulse oximetry device for daily measuring of heart rate and oxygen saturation transmitted wirelessly from the tablet application to the telemedical centre (TMC). The software also included a questionnaire to measure patients' subjective symptoms and self-evaluation. The full TM intervention consisted of the technical solution, monitoring and follow-up by nurses working in a TMC.

In total, the intervention lasted for three months. For the first two weeks after discharge from the hospital, the intervention consisted of daily contact between patient and a trained TM nurse. This included evaluation of transmitted health data and follow-up with video communication. After two weeks, and in collaboration with each patient, the daily video contact was reduced to two to three times a week. However, the TM nurse still assessed the transmitted health data daily. At this point, the TM nurse would contact the patient if his or her health data fell outside the normal range. If health data were not received by a set time every day, the TM nurse would contact the patient. After approximately 30 days, the follow-up was completed, and the patients returned the TM equipment to the local hospital. For the next two months, the patients had the opportunity to get in contact by telephone with a TM nurse at the TMC for advice.

3.3 | Participants

The inclusion criteria were that the patients had been followed up between one and three months during the TM intervention and had returned the TM equipment to the local hospital. All patients who fulfilled these criteria were asked by a trained TM nurse at the TMC if they would participate in the study. The nurse gave initial information about the study and that participating was voluntary. Those patients who were interested were phoned by the first author and had the opportunity to ask questions and give oral consent or to withdraw from participating in the study. Two of twelve contacted patients wished to withdraw. Ten participants were included in the study; three women and seven men ranging in age from 61–80 years, with a mean of 72 years. In addition, the severity of COPD ranged from moderate to very severe (Vestbo et al., 2013). See Table 1 for demographic characteristics of the participants.

3.4 | Data collection

Data were collected by in-depth interviews over an eight-month period in 2015 from January–August. Nine of the 10 interviews were conducted at the participants' home, and one took place at the local university. The participants were encouraged to narrate their own lived experiences. The interviews consisted of two open questions: "Please, tell me about a situation when you could improve your quality of life as a result of being included in the TM intervention" and "Please, tell me about a situation when you could not improve your quality of life as a result of being included in the TM intervention." To go into more detail and guide the conversation, further probing questions were asked, such as, "Can you tell me more about that and can you describe this further?" Using a descriptive phenomenological research method, it was important to focus on the lived experiences of the participants, and this methodological ideal underlines letting the participants tell their experiences openly and freely (Giorgi, 2009). The interviews were audiotaped and transcribed verbatim and lasted from 30–50 min, with an average of 38 min (see Table 1).

3.5 | Data analysis

The data were analysed using a descriptive phenomenological research method with the following four steps (Giorgi, 2009):

1. The text was read to get a sense of the whole.
2. The text was read repeatedly, and meaning units were established.
3. Meaning units were transformed from the participants' everyday language into a health science perspective emphasising the phenomenon being investigated and using free imaginative variations relevant to the perspective.
4. All meaning units were synthesised into a consistent statement (situated structure) of the structure of the phenomenon for each

TABLE 1 Participants' characteristics

| Participant | Gender | Age | Chronic obstructive pulmonary disease severity ^a | Living arrangements | Length of interview (min) | Included in intervention (weeks) |
|-------------|--------|-----|---|---------------------|---------------------------|----------------------------------|
| A | Male | 74 | Moderate | With spouse | 48 | 4 |
| B | Female | 74 | Severe | With spouse | 37 | 6 |
| C | Male | 61 | Very severe | Alone | 40 | 8 |
| D | Male | 75 | Severe | With spouse | 32 | 4 |
| E | Male | 63 | Very severe | Alone | 35 | 5 |
| F | Male | 80 | Moderate | With spouse | 30 | 4 |
| G | Male | 75 | Very severe | With spouse | 31 | 4 |
| H | Female | 77 | Severe | Alone | 50 | 6 |
| I | Female | 73 | Severe | Alone | 29 | 6 |
| J | Male | 70 | Moderate | With spouse | 48 | 6 |

^aModerate: mild or moderate airflow limitation with low risk of exacerbation. Severe: severe airflow limitation with high risk of exacerbation. Very severe: very severe airflow limitation with high risk of exacerbation (Vestbo et al., 2013).

TABLE 2 The participants' experiences of living with chronic obstructive pulmonary disease (COPD) and receiving care through telemedicine (TM)—illustration of the analytic procedure

| Meaning unit | Transformation—free imaginative variations relevant to health science | Themes |
|--|---|--|
| D: I can't do the things I normally could do because I can't breathe. Like shovelling snow... My wife has to do it for me now | Limitations caused by the disease lead to loss of function | Living with COPD: physical and emotional limitations |
| H: I experienced that I had a nurse I could talk to every day (...) I felt safer | Daily follow-up provides safety | Receiving care through telemedicine (TM): accessibility, support, clinical insight, mutual clinical language |
| G: I could even see my measurements! When the measurements were abnormal the TM nurse would contact me, and I got answers and confirmation. Otherwise, I would worry | Clinical measuring provides information and confirmation on a daily basis | |
| J: I have to plan more, know that I have TM. I am not sure that this could replace the security (...) I felt "locked" to a certain time | TM causes the participant to be bound in time and place | The dual chore of receiving care through TM |

interview. The situated structures formed the general structure of the lived experience of living with COPD and receiving care through TM.

An example of the analysis is illustrated in Table 2.

3.6 | Ethical consideration

The research was designed and performed in accordance to the Declaration of Helsinki (Declaration of Helsinki 2013) and common principles used in clinical research (Beauchamp & Childress, 2013). The study was approved by the NSD—Norwegian Centre for Research Data (project number: 41146). Before conducting the interviews, the participants were informed about the study, and their written consent to participate was obtained. In addition, they were notified that they could withdraw from the project at any point and that their confidentiality would be assured. As the interviews were conducted with participants who were severely ill, an

important aspect was the participants' dyspnoea. Thus, the length of each interview was based on the participants' health status at the time of the interview. Despite some pauses, the interviews were conducted as planned.

4 | RESULTS

4.1 | General structure

Living with COPD was experienced as creating physical and mental limitations of the diseased body and an increasing identity as a patient, which led to impaired quality of life. Being included in the TM intervention increased accessibility to healthcare services and support from TM nurses. Self-measurement of health data increased participants' clinical insight and created a mutual clinical language in dialogue with TM nurses, which led to increased quality of life. However, receiving care through TM was also experienced as a dual chore (Table 3).

TABLE 3 The results presented as themes and subthemes

| Themes | Living with chronic obstructive pulmonary disease: physical and mental limitations | Receiving care through telemedicine (TM): accessibility, support, clinical insight and mutual clinical language | The dual chore of receiving care through TM |
|-----------|--|---|---|
| Subthemes | Limitations of the diseased body | Accessibility | |
| | Limitations of the increasing identity as patient | Support | |
| | | Clinical insight | |
| | | Mutual clinical language | |

4.2 | Living with COPD: physical and mental limitations

The participants were mostly concerned about their own health status and shared past and present disease experiences and experiences related to the healthcare system. The stories told were descriptions of the lived experience of COPD, stories of physical and mental limitations related to the diseased body, and the identity as a patient, which all reduced the participants' quality of life.

4.2.1 | Limitations of the diseased body

The participants narrated the experience of living with COPD; and how the condition affected both body and mindset, as a perceived limitation in their everyday life. Several participants experienced increasing difficulties with everyday activities, for example, shovelling snow, going to the store or doing housework. These activities often had to be transferred to their spouse or next of kin:

I cannot do the things I could normally do because I cannot breathe. Like shovelling snow... my wife has to do it for me now. (Participant D)

As a result, becoming dependent on medicine, equipment, or other persons led to a sense of loss, with significant impacts towards feeling connected to losing control over their lives. As the body became weaker and dyspnoea worsened, emotions connected to fear, stress, and anxiety increased. One participant narrated how he felt he was in captivity; his diseased body controlled him, and he was afraid of experiencing breathlessness and anxiety. As a consequence, he felt forced to live a passive and isolated life:

[...] when I experience breathlessness, I lose control, and then my anxiety kicks in. I have to learn to live with the anxiety at one level, then the next stage comes, and it gets worse... So, it [the disease] is constantly deteriorating! It is absolutely terrible... I spend a lot of time sitting inside, it is not nice at all, but it has just to be like that. (Participant C)

The limitations of the diseased body were perceived differently between the participants. One participant explained that she needed to modify her social life when she could no longer control her breathlessness and anxiety. Her body became a confinement to her,

enhancing the feeling of loneliness, and being with friends and family was perceived unmanageable:

[...] so overall my life style has deteriorated very much. I cannot cope with many things, I cannot be the person as I used to be... Before, I was able to do more social activities. Last Saturday, for example, I tried to go out with my friends to a concert, but there was so little air at the venue, so when I had been there for 20–30 min, then it was over. I just had to find my way out... and take a taxi home to recover. (Participant H)

Another participant had to give up hunting, which was his passion. The diseased body was experienced as reducing mobility, while the instability of the disease created anxiety, and both prevented social participation.

4.2.2 | Limitations of the increasing identity as patient

When the participants described what it was like to live with the disease, they described how several past and present healthcare experiences had influenced their current life. Experiences of disease exacerbation were a reminder of how the illness had evolved, with increasing worries regarding the future. Past experiences related to COPD thereby gave focus to a constant fear of experiencing new disease episodes:

I usually get two serious infections a year after I developed COPD... that is when I get really sick! There were infections with so much mucus, and it was like glue! And I could not get the mucus out! And I got a sensation of cramped breathing [...], and eventually I ended up gagging to try to get the mucus out. There are many things at once affecting my quality of life. Also, there is the... the fear! I am afraid I will start to suffer like that again. (Participant H)

The last time I had it [experienced exacerbation], I ended up in hospital, then I was sure that I would not come out again. So, [...] as it [the disease] deteriorates... I know I am going to get some 'down' periods. (Participant A)

The evolving disease increased the need for healthcare services and thus fostered the participants' identity as a patient.

Several participants had experienced negative episodes with healthcare services, which often involved not being taken seriously when trying to seek help for dyspnoea and disease exacerbation:

I have had negative experiences with the Emergency Department (ED), sometimes I have been sent home with pain killers and other things [...] it is experienced differently in the ED, dependent on who is at work. (Participant D)

This experience was an apparent frustration when dyspnoea was experienced as a struggle in itself. They also found it a struggle to get medical attention for their health problems. Consequently, several participants had developed an increasing uncertainty towards healthcare professionals and the healthcare system. Some participants narrated how these experiences had led to hospitalisations when the exacerbation was not treated in time due to the reluctance towards seeking timely treatment. Such experiences led to an increasing identity as patient.

4.3 | Receiving care through TM: accessibility, support, clinical insight and mutual clinical language

Closely related to the stories about physical and mental limitations were the stories about how TM was perceived as improving accessibility to healthcare services and support by TM nurses and providing clinical insight and a mutual clinical language, which in turn increased quality of life.

4.3.1 | Accessibility

Having daily contact with the TM nurse through the TM equipment was perceived as improving accessibility to healthcare services, especially when in need of help. This improved participants' sense of security and peace of mind, knowing that they were monitored every day. The improved accessibility also increased peace of mind of family members and relatives. The participants narrated how their family members knew that competent health professionals, thus improving predictability, were monitoring them:

It has been a big improvement for me that my children know that I have been followed up, they do not call and make a fuss about it with me... and THAT is, it made my life situation a lot better! To be self-reliant and... and to experience everyday security... I think it has helped me to breathe, to be safer. (Participant H)

Furthermore, the care received through TM was experienced as near despite the geographical distance between the participant and TM nurse. Several participants narrated that the real-time video contact gave them the feeling of "being in the same room" with the TM nurse:

That was nice [using videoconference]. It is okay using phones and that sort of thing, but it is... it is a lot

better! It is just like, yeah that... like as we sit now, it is much more contact than it would have been by using phone and other things. (Participant F)

This impression increased the sense of accessibility, with the real-time video contact representing an important aspect for achieving it. When in conversation with the TM nurse through video, several participants experienced that the TM nurse focused all the attention towards them and that this provided individual attentive care despite the distance. The opportunity to see the TM nurse on the screen was considered crucial and compensated for not being in the same room.

4.3.2 | Support

Through the TM equipment, the participants experienced improved support from the TM nurse. This support and regular follow-up resulted in an increased awareness towards the diseased body regarding symptoms, ability and emotions. The support was important to get information on health status, feedback and advice that was qualified and trustworthy. Thus, the given support was felt as reassuring; one participant described how she often felt unsafe at night, experiencing breathlessness, fear and anxiety. When she woke up, the first thing she wanted to do was to consult with the TM nurse. The prompt response to her regular clinical readings, whether normal or abnormal, followed by advice and guidance, provided her with reassurance. This information from the TM nurse was very important to her, especially on the days she was not feeling well:

It was difficult at night, thinking; I am not feeling well. I wanted to talk to the TM nurses in the morning... they could say; you can wait and see, if this worsen you can start with medication if you feel that you need it... It was reassuring. (Participant B)

The participants acknowledged the personal connection with the TM nurse, which gave them a feeling of being known. However, it was perceived as similarly important that the TM nurse had adequate competence in both illness and personal health history of each participant to cover both medical and emotional needs. The participants described that the TM nurses understood how their individual limitations were connected to the diseased body:

I think that is [connection with nurse] very nice, because they understood what I was talking about... on everything! If I said that: oh! Today I experience breathlessness! Yes, what have you done? Then the TM nurses accept you, right, and then they ask, how do you feel? and that kind of thing. It is a completely different way to connect and I get positive effects to talk to someone like that. (Participant B)

4.3.3 | Clinical insight

When participating in the TM intervention, the participants performed daily self-measurements of clinical parameters including oxygen level and heart rate. The daily measuring was perceived to increase clinical insight. Two key elements were apparent: First, daily clinical insight improved coping with the recurrent fear of disease exacerbation and breathlessness by giving an overview of disease development. This provided participants with knowledge on their own health status and progress. Additionally, it was important that the daily measurement was provided promptly, as the quick response helped participants to cope with the fear of breathlessness:

It is all about safety and the contact of course, because I knew... if I had abnormal readings, they would be there right away! Call me up, and ask me what I had done. (Participant E)

Second, clinical insight strengthened the participants' self-reliance. Access to clinical information was experienced to improve self-management, thus increasing engagement and involvement to learn more about their own health condition:

Well, to get an answer yourself, to feel safer, and try to think back; what have I done now since the heart rate is so high? Also, that when it started to go down to normal... that was very reassuring, in that respect. (Participant E)

I thought somehow; what have I done now? To get my heart rate to rise so much! So, then I had to somehow work out... oh well, I took the garbage outside or something like that... (Participant I)

This insight into clinical measurements increased the ability to compare daily measurements with the experienced symptoms related to COPD. The clinical measurements ameliorated the uncertainty regarding symptoms and contributed to separate anxiety from exacerbations, which had been difficult before. In addition, the increased self-reliance provided participants with confidence to be more involved in their own health.

4.3.4 | Mutual clinical language

The participants described how the daily clinical measurements, which were sent to the TM nurses on a daily basis, provided a mutual clinical language. This was perceived to increase the knowledge about the significance of each value and what it represented. In particular, measuring oxygen levels provided a visual numeric message, which increased the participants' knowledge and awareness on clinical readings so that they could understand both normal and abnormal values:

If I had a bad day, I could measure it [saturation] you know, if I felt bad you know... then I could insert my

finger in the machine there, too, I could see that it was 94 or 91 [saturation], but if it was under 90, then I knew it was bad. (Participant G)

This led to increased understanding of individual health development, both for the participants and for the TM nurse, improving collaboration and dialogue and thus strengthening the relationship with the nurse. This relationship between participant and TM nurse was experienced as collaboration. TM contributed to an increased level of active participation in the own treatment:

When my oxygen [saturation] were low the nurses would contact me... we made a plan, together. It was good to make a plan. (Participant C)

The daily follow-up on clinical measurements helped to discover health problems related to COPD in time. Similarly, the participants felt acknowledged when their experiences connected to health status could be verified with the use of the numeric and mutual clinical language. As a result, they experienced to be taken seriously by the TM nurse. One informant reported that when his clinical measurements were abnormal, the TM nurse would contact him, and he would get answer and confirmation; otherwise, he would continue to worry:

I could even see my measurements! When the measurements were abnormal the TM nurse would contact me [...] and I got answers and confirmation, otherwise I would worry. (Participant G)

Increased knowledge and the mutual clinical language contributed to the participants' experience of being heard and taken seriously by healthcare professionals.

4.4 | The dual chore of receiving care through TM

The technology used in the TM intervention was perceived as easy to use and manage. Several participants acknowledged that they felt safer in the transition from hospital to home because of the follow-up through TM. However, when the TM technology failed, the real-time video dialogue was replaced by conversations through mobile phone. This reduced the accessibility and support. As a consequence, many of the positive aspects that the TM equipment initially provided were removed:

It was very nice to talk with the nurses if I felt something was wrong, but the quality on the tablet was so poor [...] many times it did not work! [...] only a few times I was able to talk face to face. I missed that type of contact a bit. (Participant B)

Although all the participants perceived the TM intervention as positive, there were nuances related to disease severity. A clear

dissociation between severity of COPD and the experience of receiving care through TM was found. Receiving care through TM was sometimes perceived as an impediment for the participants with moderate COPD severity:

I have to plan more, now that I have TM. I am not sure that this could replace the security... I felt 'locked' to a certain time. (Participant J)

They believed that the TM equipment constrained them in time and place compared to before the intervention, because their need for support and accessibility was reduced when they were in good health. First, the intervention consisted of scheduled contacts with the TMC, and the participants had to plan their day in relation to the TMC program. When family routines conflicted with the TM service, the technology was abandoned or resulted in delayed measurements and dialogue. Second, TM occasionally increased the focus towards the condition and related symptoms when in good health. This led to an unwanted and increased focus towards the illness.

In contrast, the participants with severe or very severe COPD did not experience the TM intervention as an obstacle. The condition for these participants was characterised by increased limitations associated with disease severity, making it difficult to participate in other activities due to constant dyspnoea. These participants wanted daily follow-ups and over a longer period. They also desired to continue with TM even when the intervention ended.

I am going to miss it... there is no doubt about that. The peace of mind, and the contact [support]. (Participant E)

In addition, some participants also reported becoming increasingly addicted to the oximetry device, experiencing a negative impact on quality of life.

5 | DISCUSSION

The aim of the present study was to describe the lived experiences of quality of life among a group of patients living with COPD who were included in a telemedical intervention after hospitalisation for disease exacerbation. In contrast to previous research on this topic, the approach used in the present study was a descriptive phenomenological research method, allowing for more detailed and in-depth descriptions of the participants' life. The obtained data revealed a complex image. The participants described their experiences of living with COPD as limitations caused by the increasing symptom burden. In contrast, receiving care through TM contributed to reducing these limitations. However, there was a clear distinction related to the severity of COPD and the experience of receiving care through TM. The findings will be discussed in detail below.

5.1 | Unlocking the limitations of COPD through telemedicine

All of the participants experienced how the diseased body led to loss of function and control, and as a consequence, decreased their abilities in daily life. Many patients with chronic conditions, and especially those with COPD, experience a high degree of unpredictability due to ever-changing symptoms (Ek & Ternstedt, 2008; Gardiner et al., 2009; Simpson & Rocker, 2008). These patients often report great benefits of TM in managing COPD compared to usual care (Brunton, Bower, & Sanders, 2015; Pols, 2006). Similarly, the TM intervention in the present study was perceived to be of great benefit by increasing accessibility to healthcare services. An important aspect of accessibility was the tentative focus and responsiveness to individual needs by TM nurses, as previously supported by Fairbrother et al. (2012), Gale and Sultan (2013), and Gorst et al. (2016), which improved security and peace of mind.

Several studies have expressed concerns that TM would replace hands-on-care and human contact (Gale & Sultan, 2013; Mort, Roberts, Pols, Domenech, & Moser, 2013) and could not perform sufficient care on its own (Greenhalgh et al., 2013), and as a consequence, would contribute to poorer care and less interaction between patients and healthcare professionals. However, our findings demonstrated that the regular follow-ups from TM nurses through TM and video consultation were experienced as the opposite and similar to near care despite the geographical distance between participant and TM nurse. The video consultation was a key contributor to strengthen the patient–nurse interaction due to the possibility to see the TM nurse. Therefore, the TM equipment functioned as a facilitator for closer contact. The significance of the nurses' presence and care through TM compensated for not being in the same space. In addition, the focused attention from TM nurses facilitated by the video consultation could increase the closeness to health professionals and amplify the focus on the patient, unlike regular care where patient contact comprises a list of practical tasks. Similarly, Pols (2006) found that TM technology did not put care at a distance but rather in close proximity. Furthermore, Vatnøy et al. (2016) found that face-to-face contact by means of TM and video consultation was meaningful for individuals with COPD.

The TM nurses were of great importance in providing support, and the findings highlighted the difference between traditional care and TM services; that is, the TM nurses could respond promptly when the participants were in need. In addition, the regular support and encounters with the TM nurses provided better follow-up on the unpredictable changes and limitations of the diseased body. The participants in the present study experienced the daily follow-up as reassuring, compared to seeking contact only when health was deteriorating, as in regular care. This meant that both the medical and social challenges of the illness were addressed, and emphasises that giving medical information and advice via video can also be seen as a way of caring. TM can function as a new form for communication with healthcare professionals (Pols, 2006) and increase accessibility

and support. According to the participants, this reduced the limitations of the diseased body and increased quality of life.

One of the symptoms the participants described as the most difficult to handle and endure was breathing difficulty. The high symptom burden of COPD is often combined with poor symptom control (Gardiner et al., 2009), and increased dependence on others affects the person's identity and self-esteem in a negative way (Ek & Ternstedt, 2008). Fear and anxiety are also closely connected to breathlessness. To cope with fear, TM can contribute to a reduction in symptoms, such as breathlessness (Pols, 2006), through self-measurement, which was apparent in the present study. Poor symptom control creates greater requirements for care (Gardiner et al., 2009) where the patients are in the centre of the care effort (Simpson & Rocker, 2008).

The findings showed that the participants became more involved and engaged in their illness when performing daily self-measurements. This led to increased clinical insight and overview over the evolving disease. In turn, this provided a better understanding for both present and future health development and contributed to putting the participants in the centre of care with increased control, independence and confidence in their life. Furthermore, self-management is highlighted as an important aspect for individuals living with COPD to become more active and involved in their illness (Simpson & Rocker, 2008). Further, several studies (Gorst et al., 2016; Vatnøy et al., 2016; Williams et al., 2014) have emphasised that TM can promote self-management.

Moreover, the current findings showed that clinical insight led to the development of a mutual clinical language. Mort et al. (2013) advocated TM system designs to facilitate horizontal and interactive communication rather than vertical communication, which is common in regular healthcare services today. Consistent with our findings, Williams et al. (2014) found that the monitoring through TM care increased patients' awareness, developing an understanding for normal levels of clinical readings. However, the present findings extend this research, as self-measuring not only increased understanding but also contributed to horizontal communication and strengthened the participants' acknowledgement, collaboration and dialogue with the TM nurses. As a result, this enhanced a more open communication approach to healthcare professionals, providing a more equal and common understanding while allowing the participants to engage with their individual health challenges. This in turn reduced the limitations of the identity as a patient and further increased quality of life.

However, there are still contradictions when caring through TM (Brunton et al., 2015). The present study found that COPD severity, varying from moderate to very severe, influenced how receiving care through TM was perceived. Although participants with moderate COPD severity experienced the TM intervention as positive, they also found it to be a burden. The low symptom burden in moderate COPD enhanced the ability to be more active and independent. In these cases, TM made the participants feel more restricted in time and place and unnecessarily increased their focus on the illness, bringing care too close, which made the illness more dominant in their lives. Similarly, Pols (2006) and Brunton et al. (2015) found that care can be harmful when it increases the focus towards the illness

rather than reducing it. This shows that the benefits of TM are perceived differently based on disease severity.

Although this phenomenological study contributes to new knowledge regarding the experience of living with COPD and being followed up through TM, it is important to acknowledge some limitations concerning the research method. It is important to be true to the principles of phenomenology to reach trustworthiness in phenomenological research (Söderhamn, 2001). The present study included ten participants, and it could be argued that this sample was too small. However, in phenomenological studies, large samples are not required, because such research enhances the in-depth knowledge of the participants' life. To achieve such knowledge, all pre-understanding has to be bracketed (Giorgi, 2009), including the authors' pre-understanding as nurses. Nevertheless, to bracket one's pre-understanding can be challenging. However, to prevent swaying the findings, most of the previous studies were consulted after having performed the analysis.

The analysis was shared and discussed with co-authors. In addition, an example of the analysis (Table 2) shows how the raw data, the different meaning units, the free imaginative variations and general structure were elaborated. This verifies the findings and further contributes to trustworthiness. The subjectivity of the data can lead to difficulties in establishing reliability and validity of the methodological approach, and the information it provides. In the present study, the validity of the findings was confirmed by carefully following the analysis steps when searching for the essence in the interview texts. Further, the reliability of the findings was confirmed through the same meaning occurred in the interview texts (Söderhamn, 2001).

6 | CONCLUSION

The increasing care burden on patients with COPD exemplifies the need to reconsider how care is provided. TM can fulfil several unmet needs for patients suffering from COPD, which traditional care has not been able to provide. The findings in the present study show that TM can reduce the perceived limitations of living with COPD through four key elements that reshape the models of care: (i) improving accessibility to healthcare services, (ii) increasing support from health professionals, (iii) strengthening clinical insight and (iv) developing a mutual clinical language, which all contribute to increasing quality of life. The transparency facilitated through TM in this healthcare context encourages open decision-making, where the participants can increase their knowledge, improve acknowledgement of and collaboration with TM nurses, and as a result, experience that they are taken seriously in terms of their health problems.

7 | RELEVANCE TO CLINICAL PRACTICE

The findings in the present study promote new implications for practice and rethinking of care and provide important information on

how living with COPD can affect the experience of receiving care through TM. In addition, the present study highlights that patients with severe and very severe COPD are the ones that find TM the most useful when managing their illness. This knowledge can further determine for whom TM is useful and contribute to clinical practice by providing care to those patients who would benefit the most. However, future research, both qualitative and quantitative, is needed to obtain further knowledge on the patients' experiences of receiving care through TM. In addition, TM interventions should be extended over a longer period to fully understand the challenges of living with COPD and further explore for whom TM is most useful.

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CONTRIBUTIONS

Study design: TLB, ET, US; data collection: TLB. TLB analysed the data and discussed the analysis with ET and US. TLB wrote the manuscript and ET and US reviewed it. All authors approved the final version.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

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