

Living in the Wake of Chronic Obstructive Pulmonary Disease and Long-Term Oxygen Therapy

Malin Axelsson¹, Lena Persson², Birgitta Höglund-Nielsen³

¹Department of Care Science, Faculty of Health and Society, Malmö University, Malmö, Sweden

²School of Health and Society, Kristianstad University, Kristianstad, Sweden

³City of Copenhagen, Copenhagen, Denmark

Email: malin.axelsson@mah.se

Received 5 April 2016; accepted 7 May 2016; published 10 May 2016

Copyright © 2016 by authors and Scientific Research Publishing Inc.

This work is licensed under the Creative Commons Attribution International License (CC BY).

<http://creativecommons.org/licenses/by/4.0/>



Open Access

Abstract

Background: Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the world. COPD is a progressive disease that could lead to chronic hypoxemia, which requires treatment as domiciliary Long-Term Oxygen Therapy (LTOT). There is a need for increased knowledge about self-care strategies used by individuals living with COPD and LTOT. **Objective:** The aim was to explore experiences and self-care strategies in patients living with both COPD and LTOT. **Sample:** The sample consisted of five men and five women diagnosed with COPD being prescribed LTOT for more than one year. **Method:** Ten interviews were undertaken and analyzed for both manifest and latent content. **Results:** Living with COPD and LTOT was associated with experiences of guilt although there were doubts about what had caused the lung disease. Both the lung disease and the oxygen therapy had a negative impact on their self-image. Anxiety was expressed when thoughts about the remaining time occurred. There was a constant balance between diminishing abilities and increasing restrictions related to the lung disease and the therapy. In order to compensate for arising imbalance, self-care strategies had been initiated aimed at preserving the present state of health, enabling and facilitating physical activity and promoting a positive attitude. **Conclusion:** The current study suggests that individuals living with COPD and LTOT are encouraged to adopt self-care strategies directed towards maintaining stability with regard to the lung disease, the oxygen therapy, physical capability and emotional reactions.

Keywords

Disease Management, Patient Experiences, Respiratory Tract Disorder, Self-Care Strategies, Qualitative Research

1. Introduction

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the world [1]. The prevalence of COPD varies across countries and is associated with the prevalence of tobacco smoking, which is the most common risk factor for the development of COPD. COPD is associated with dyspnea, chronic cough and sputum production [2]. Living with COPD means a consistent struggle against dyspnea [3] [4] feelings of anxiety, fear [4] [5] and an overwhelming fatigue [4] [6]. The daily life deals with avoiding activities leading to a troublesome breathlessness [7] and striving for an adjustment to limitations in daily life caused by breathlessness [8]. Experiences of not being met with understanding [7] and feelings of physical, social [7] [9] and existential isolation [9] have also been described.

COPD is characterized by progressive and chronic airway inflammation as a response to inhaled tobacco smoke and other harmful particles. The inflammation leads to pathological changes of the small airways and the parenchyma, which causes airflow limitation. Smoking cessation is the most important part of the treatment because it has the strongest impact on the disease progression. Pharmacological treatment is used to reduce symptoms and frequencies and severity of exacerbations and to improve health status and exercise tolerance. Non pharmacological treatment options as pulmonary rehabilitation are used to reduce symptoms and to improve quality of life for instance [2]. Long-Term Administration of Oxygen of at least 15 hours a day has proven to increase survival in individuals with severe COPD who develop respiratory failure with severe chronic hypoxemia [10] [11]. However, living with LTOT could be associated with feelings of being restricted in everyday life both due to the oxygen equipment but also due to the dependence on oxygen many hours a day [12]. Ek and colleagues found that individuals living with advanced COPD and LTOT experienced their everyday life as a struggle to retain their living space and experiences of being restricted [13]. Despite the restrictions following the oxygen treatment, LTOT in individuals with COPD could have a positive impact on health-related quality of life [14].

Self-care is essential in order to manage in everyday life when living with a chronic illness and could be viewed as a process involving behaviors that are used to maintain illness stability as well as both physical and emotional stability and to promote well-being. Self-care can reflect recommendations from health care professionals as for instance a prescribed treatment [15]. Self-care also entails those activities that individuals initiate and perform on their own behalf in order to maintain well-being [16]. Supporting individuals with COPD with their self-care management has a positive impact on health-related quality of life, improves dyspnea and decreases hospital admissions [17]. It has been suggested that increased knowledge about how individuals with COPD make sense of their illness could be useful in refining self-care management [18]. However, few studies have addressed self-care strategies in individuals living with both COPD and LTOT. It could be hypothesized that increased awareness of individuals' experiences of living with COPD and LTOT and their self-care strategies could be useful in efforts to refining self-care management for this group. Thus, the aim of this study was to explore experiences and self-care strategies in patients living with both COPD and LTOT.

2. Materials and Methodology

2.1. Sample

The sample consisted of ten patients, five men and five women, registered at a pulmonary unit at a hospital in the south of Sweden. All of them were diagnosed with COPD and chronic hypoxemia and had used LTOT at least 16 hours a day (according to local recommendations) for more than one year. The sampling was made consecutively from the home-visiting list of the oxygen nurse. She passed information about the study to the patients when making a home visit. If the patient seemed interested he/she was given a letter of information and was asked if she was allowed to give the patient's name and phone number to the investigators. The oxygen nurse delivered letters of information to 13 interested patients. Three were excluded due to worsening in the COPD which made participation impossible.

2.2. Data Collection

Semi-structured interviews were used to collect data. The interview guide covered areas concerning the informants' managing in everyday life living with COPD and LTOT with regard to physical and emotional impact, activities, social contact with family and friends, about which they were asked to speak freely. They were also

asked to share their experiences of living with COPD and LTOT. The interview started with an open question: “Can you tell me about an ordinary day?” This question was followed by probing questions such as: How do you feel about that?, Could you tell more about?, How are you thinking about that?, Could you give an example?, Could you explain this further?. Nine of the interviews took place in the informant’s home, one in a secluded room at the hospital. The interviews lasted 60 - 90 minutes and were performed between June 2004 and January 2005.

2.3. Data Analysis

The interviews, written verbatim, were analyzed by a movement between latent and manifest content analysis [19]. The former was seen as the deep structures in the text; the analysis implied an interpretation of the underlying meaning. The latter was understood as the superficial structure, the visible and obvious. The interviews were read through several times to gain an overall picture of the content. Separate words or short phrases conveying important information were highlighted and noted down in the margin as meaning units—the open coding. Then the units were cut down into a gigantic jigsaw puzzle in which the “pieces” were grouped and sorted in subcategories according to content. The subcategories were compared considering similarities and differences. The condensed meaning units were supposed to belong only to one subcategory that resulted in the formulation of separate categories. In the last phase the interviews were read through as a whole once again in order to recapitulate the statements of the informants and to have the context fresh in mind when formulating the result.

2.4. Ethical Considerations

The informants were informed that their participation was voluntary and that they could end it without explaining why and that it would not affect care or treatment. The collected material was handled confidentially. Informed consent was given in writing by the informant before the interview started. The Ethics Council of Kristianstad University gave its approval for the study, 2004-2005, as did the head of the medical clinic and the head of the lung and allergy section.

3. Results

The informants were born between 1924 and 1939. Five lived alone, five were cohabiting. Nine lived in ordinary homes and one at a nursing home. Three received help from community care. The others were dependent on their relatives. The analysis emerged into three categories: living in the wake of COPD and LTOT; balancing between diminishing ability and increasing restrictions; and self-care strategies for managing in everyday life (Figure 1). The categories were composed by the subcategories presented in Table 1.

3.1. Living in the Wake of COPD and LTOT

Experiences of living with COPD and LTOT involved feelings related to the cause of the disease, impact on their self-image and the interference of the treatment in their everyday life.

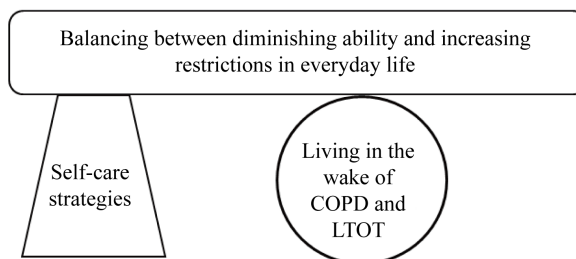


Figure 1. Model illustrating that living with Chronic Obstructive Pulmonary Disease (COPD) and Long-Term-Oxygen Therapy (LTOT) gave rise to an everyday life characterized by a balancing between ability and restrictions in everyday life and that self-care strategies were initiated and performed to avoid instability in everyday life.

Table 1. Categories and subcategories describing experiences and self-care strategies.

Categories	Subcategories
In the wake of COPD	Guilt and doubt Emotional adaption Adaption in time and place The time remaining
Balancing between diminishing ability and increasing restrictions	I am out of breath all the time Restriction in the manner of living Restrictions in social relations Dependence on others
Self-care strategies for managing in everyday life	Preserving the present state of health Pacing and controlling Striving for a positive attitude

3.1.1. Guilt and Doubt

Several of the informants spontaneously shared their speculations concerning the cause of the lung disease. Feelings of guilt appeared, as they felt that they had not looked after their health in a satisfactory manner: *“I’m ashamed because of this... Yes, because I’ve caused it myself. It’s an unnecessary disease”* (08). Some expressed regret for once having smoked, as they were of the opinion that smoking was the cause of their present situation in life. They were critical of themselves: *“I’ve been so foolish... I mean the smoking... I had such a good doctor... and he said to me, ‘You must give up smoking’, he said. But I didn’t listen. I didn’t listen to him”* (03).

Even though the informants expressed an awareness of the risks of smoking, they were also doubtful. *“Because they say it’s the smoking that caused COPD but I don’t believe it’s the smoking”* (07). Being met with injustice was a common feeling: *“Of course you think, why should it strike me of all people? There’s millions of people smoking. If the cigarettes really are to blame”* (02).

The lung disease nourished a sense of guilt that affected the informants’ self-esteem in a negative manner, which led to them avoid showing symptoms like dyspnea in public. *“I stand leaning over the trolley and leaning forward and standing someplace behind where I can’t be seen”* (03). Due to unwanted attention, several avoided going out using the oxygen therapy. *“It has been difficult and I don’t like to go into town with the nasal cannula and have it in my wheelchair, so they can rather think I have broken my leg or anything but not this”* (08).

3.1.2. Emotional Adaption

It was difficult in the beginning to adapt emotionally to the oxygen therapy. Discipline was required for adherence to the therapy. *“Yes, of course, as I said, in the beginning, it was no fun. Then I really was depressed. ... then everything was ruined”* (10). As time passed, several of the informants felt that the adjustment had turned out beyond their expectations. That was explained by them as understanding the cause and effect of the therapy. *“Because I wouldn’t be alive now if I hadn’t got it”* (05). *“This tube is my umbilical cord. I have to be careful with it”* (02). Most of them expressed gratitude for having received the treatment. *“I am very grateful for my oxygen”* (06).

3.1.3. Adaption in Time and Place

The informants used the oxygen therapy at regular hours because it made them feel well. Usually they had the therapy in one go from early night until forenoon. After that they were free for a couple of hours during the day-time. Only in exceptional cases did they undertake anything during the so-called oxygen hours; they preferred to adjust their activities to the oxygen-free hours. *“I have to try myself if there’s something I’m going to do... then I have to try and get a time in the afternoon and usually there’s no problem”* (06). Even though most of the informants stated that the adjustment to the oxygen therapy went rather well, they felt bound to their homes. The

hours of the oxygen therapy were generally spent at home. The portable equipment, which was supposed to decrease their dependence, was generally not used on weekdays but on special occasions such as short journeys or excursions.

Being aware of the development of the lung disease and the fact that there was no cure, the informants nourished hopes that research in the future would find new treatments or even a cure for COPD. *“The only dream, if you like, that I’ve got is that more research should be done about the lungs so they could find some medicine...”* (1).

3.1.4. The Time Remaining

They did not bring the future up for discussion, but when asked they expressed severe anxiety when thinking about the time remaining. *“I wouldn’t wish this on my enemy if it should get worse”* (07). The anxiety led their thoughts towards the end of life—with varying feelings. Some experienced agony of death, which could give rise to sleeping difficulties. Others expressed almost a longing for death because the present situation in life was experienced as a suffering. Thoughts about death were also dealt with in other ways, such as imagining how life after death could turn out, with hopes that this would be a far more pleasant existence than the present one, a place filled with harmony. *“I always long for the sea, so I think that I once lived by the sea in another life and I’m going there again in another life—then I’ll live by the sea. That’s how it is”* (08).

3.2. Balancing between Diminishing Ability and Increasing Restrictions

The informants expressed that living with a progressive lung disease with worsening symptoms and the oxygen therapy made them housebound which contributed to them constantly balancing between their diminishing abilities and increasing restrictions.

3.2.1. “I’m out of Breath, All the Time.”

The disease progressing the respiration was getting worse. The ability to function in daily activities as desired, and as the informants had been used to, became more and more restricted. Few claimed that they were able to perform almost any activity they wanted. Others could barely manage the common everyday activities.

The dyspnea set limits to the ability to move and thus determined whether activities could be carried out or not. Especially obvious for all the informants was the breathlessness when they had to hurry and the fact that moving indoors was easier than outdoors. The majority, however, found that even moving inside the house was an effort. One woman used a rollator to facilitate this. It was also suitable to lean against when a pause was needed due to shortness of breath. This woman and several of the informants described having such limited physical ability that they could hardly walk more than a few meters before they had to rest. *“And now you know your body, so I know that I can manage to the kitchen [5 meters] and sometimes in one go and the next time in two, you have to stop in the middle”* (09). Half of the informants stated that they went out daily, either to fetch the post or for a short stroll. The others wanted to do so, but could not because breathing became unbearable.

Also, common daily activities like eating strained the breathing. The intake of food had to be adjusted according to the respiration. *“And eating, I try to do during the day if I’m able to because it’s hard to eat when you have difficulty breathing”* (03). The consistency of the food had to be changed so that it was more easily chewed or easy to cut up into pieces. Plenty of time was needed at each meal.

The ability to get dressed and ready was also affected by the breathlessness—plenty of time was required. Every stage had to be done step by step, with pauses for oxygen. Showering and above all washing the hair were even more strenuous, and could lead people to skip these. *“It’s hard work... today I’m going to shower. I think of a thousand different reasons not do it that particular moment... there’s such a terrible resistance...”* (05).

3.2.2. Restrictions in the Manner of Living

The informants’ capacity to maintain their manner of living diminished as the consequences of the lung disease increasingly affected their daily living. The changes were described as more or less revolutionary. Few could still practice their normal activities to a satisfactory extent. The rest wanted to carry out leisure-time activities they had once appreciated, but could not. *“I haven’t the strength to get started...”* (08).

A number of informants dreamt about travelling, but explained that only short trips were possible nowadays. It was considered as a risk to travel too far away, as the lung disease could get worse. But there were practical

obstacles as well. *“Well, yes, as a matter of fact to fly to the Canary Islands. I miss that. I’m not allowed to. Nobody can forbid me but then I can’t take the oxygen with me and so I don’t dare”* (06).

Major changes occurred in the life of the informants, such as having to quit work earlier than expected or to move. A man had to leave his house, partly because he did not have the strength to keep it and partly because the heating in the house consisted of open fireplaces and stoves that were not compatible with the oxygen therapy. He described this loss as an emotional distress. *“I had to leave my cottage. My beloved cottage that I owned for 21 years. We were forced to move. Yes, it was hard. Damn it all! Ugh! Very, very hard! Yes, it was difficult. You can’t describe it, I tell you. Not me anyhow!”* (05)

3.2.3. Restrictions in Social Relations

The social life of the informants was affected in different ways. The choice of living without a partner could be one outcome. *“Then I’ve wanted to be alone because of this [the oxygen] so I think it’s nice to be alone”* (06). A few of the informants could still drive, which made it easier to visit family or friends, but several did not have strength enough to leave their homes, which prevented them from living a socially active life.

Desires to participate in family matters were stated in several of the interviews, but it was not possible to fulfil them to the required extent. Efforts were made to maintain social relations; most used the telephone to maintain contact, and one man used e-mail. One problem, though, was that the impaired lung function affected the ability to converse. *“But then I’ve noticed that I can’t manage to talk that much. Sometimes I have to be a bit quieter”* (08).

3.2.4. Dependence on Others

A couple of informants stated that they did not need any help from others to manage in everyday life. The rest said that they had limited possibilities to handle necessary activities on their own, which led to dependence on others. Informants who lived alone managed thanks to community care or relatives. The others explained that they were totally dependent on their spouses to maintain the present lifestyle. They expressed an awareness of the importance of their relatives. *“Without her, I wouldn’t exist”* (07). At the same time they realized that it was a strenuous situation. Anxiety was expressed about how long this could go on and feelings of weakness were revealed. *“You know, I can’t manage to do anything, so she has to do it all. It’s hard for her. Plus, she doesn’t have the strength to do the housekeeping any longer... I don’t know what to do”* (05).

3.3. Self-Care Strategies for Managing in Everyday Life

In order to maintain illness, physical and emotional stability the informants had initiated self-care strategies that they performed in everyday life.

3.3.1. Preserving the Present State of Health

The informants tried to maintain the illness stable by thoroughly complying with the prescription of oxygen and medication and by avoiding smoking. *“No, I’m going to take care of myself and try to eat and not to smoke, take my medicine, take care of myself”* (03). Another important strategy was to be spared from infections that led to more difficulties in breathing. They were vaccinated to escape influenza and some did not shake hands when greeting people. The weather was considered to be of vital importance when it came to the risk of infection. *“Then I have to stay inside when it’s rainy and so on, then I don’t go out at all. Then I catch a cold and then it gets very troublesome. You learn to be observant of that”* (04).

Due to fear of becoming sedentary or confined to bed, it was considered important to keep the body going. Within the limits of the physical ability, they forced themselves to perform activities such as a daily walk: *“Cause we have a couple of garbage containers here and I force myself to go there, so I don’t throw everything at one time so I bring a little every now and then. Every day, consistently”* (01). A few informants took part in weekly rehabilitation gymnastics. *“But it’s very, very important to go there. Because you can’t sit in a chair the whole day. In my condition, it doesn’t work”* (05).

3.3.2. Pacing and Controlling

The informants described that they had learnt from their own experiences and had gradually come to know their ability. This knowledge led to development of self-care strategies which facilitated activities both at home and

outside. *“If I’m going to shop, as I said, I have different places and I choose the one where I can park right outside the door”* (01). Moving at their own pace strained them to the minimum and made the activity possible to accomplish. *“I’ve had to discuss with myself that I’ve got plenty of time”* (01). To control the situation and save strength, an estimation of the respiration was made before every activity. From that they determined whether it was feasible or not. *“Well, I have to make clear that today is a day when I dare to shower. That is something I can’t let them decide”* (02).

3.3.3. Striving for a Positive Attitude

Another strategy was to strive for the things in life that promoted a positive attitude instead of brooding over the difficulties. *“No, no should one start to reflect... no, hell no...”* (09). They tried to think about pleasant occasions that had happened in the past or something funny that awaited them. Social relations, especially with children and their families, played an important role. A phone call could divert the mind. A couple was active in organizational activities which were considered as a source of joy. *“And I was so happy when I was able to start singing again...”* (10).

A further way to gain a positive attitude was to try to leave their selves behind. By comparing with other people whom they apprehended having a far more troublesome situation in life, they could deal more easily with their own. This was a constant strategy among all of the informants. A man reported his observations from the rehabilitation gymnastics: *“Then I’m not ill. I see so many who are so terribly ill. I’m not ill when I’m there. I look at all those poor human beings”* (05). Such observations made their own situation in life easier to accept. *“You must be positive to learn to live with your disease. I mean, often there are those who are worse off. Indeed, there are”* (10).

4. Discussion

The current study showed that living with COPD and LTOT was associated with experiences of guilt although there were doubts about what had caused the lung disease. Both the lung disease and the oxygen therapy had a negative impact on their self-image leading to efforts to avoid showing symptoms and the therapy. Anxiety was expressed when thoughts about the remaining time occurred. It was evident that they constantly balanced between their diminishing abilities and increasing restrictions related to the lung disease and the therapy. In order to compensate for arising imbalance when living in a spiral of a progressive lung disease, it was evident that they had initiated self-care strategies that they performed in everyday life in order to maintain stability with regard to their disease, treatment, physical capability and emotional reactions.

Living with COPD means living with an incurable disease which constantly gets worse [2]. However, a medical diagnosis is not always enough for an individual to understand what consequences it will have for his/her daily life [20]. In the present study it was shown that the informants undoubtedly tried to create a comprehensible existence to be able to manage in everyday life. Based on their accumulated knowledge and individual experiences, they shaped their personal way of acting in relation to a disease in terms of self-care strategies.

The cause of the lung disease was apparent in the interviews. Expressing both guilt and doubt, the informants spontaneously mentioned previous smoking. Aversions to show traces of COPD and LTOT in public were apparent. For instance they tried to hide when symptoms occurred and they did not want to use the oxygen therapy in public. According to a study by Charmaz [21] discrediting definitions of the self may result in stigmatization. The informants in the present study apprehended their disease as self-inflicted, which apparently influenced the self and resulted in the experience of being socially stigmatized. The knowledge acquired in recent years about the harmfulness of smoking has become more common; for instance more and more smoke-free places have been created. It might just be that the opinion in society of smoking as a health hazard added to the informants’ experiences of their own responsibility and bred a sense of guilt. The informants had no clear self-care strategies to handle their sense of guilt indicating that patients need support to develop strategies to handle these feelings.

In relation to the prognosis they had formed an idea of how the lung disease would develop, like a way of predicting their future. Bearing in mind that there was no cure led to anxiety about getting worse and resulted in self-care strategies aimed at preserving the present state of health. These initiated self-care strategies are similar to what Riegel [15] describes as self-care maintenance *i.e.* self-care strategies designated to maintain stability with regard to the illness and physical and mental well-being [15]. One self-care strategy that was used to maintain stability regarding COPD that was emphasized was adherence with the oxygen therapy, which is in line

with previous research [12]. However, adherence to oxygen therapy has also been described as complicated involving concerns with the treatment in terms of social stigma, lack of perceived effect or fear of side-effects [22]. Concerns about the treatment were not expressed in the current study but the informants avoided using the oxygen therapy in public, which could be consistent with experiences of social stigma. Another self-care strategy that was performed to maintain illness stability was to avoid smoking, which is the most important part in the treatment to prevent progression of COPD [2]. This self-care strategy most likely reflected recommendations from health-care personnel. The informants also struggled to maintain physical stability by keeping the body going as strategy to counteract fears of becoming confined to bed and they adopted different self-care strategies—some seemed to benefit from participation in rehabilitation and others from daily strolls. This finding highlights the importance of encouraging patients living with COPD and LTOT to try out different self-care strategies and to evaluate which work the best.

One part of self-care is directed towards maintaining emotional stability [15], which in the current study could be seen in the informants' efforts to promote a positive attitude. They counteracted feelings of anxiety by focusing on pleasant occasions and they emphasized the importance of social relations to divert their thoughts, which is in line with previous studies [23] [24]. In addition, they tried to inspire hope or give consolation to themselves by comparisons with other people they believed had a far more difficult existence, as also found by Benzein [25]. When caring for individuals with COPD and LTOT, it is most likely of great significance to address emotional reactions and to support them in their efforts to develop and perform self-care strategies aimed at confronting their feelings in order to maintain emotional stability.

The lung disease proceeding, the dependence on others became more pronounced. This increasing dependence should be seen in the light of the strategy—pacing and controlling—in which the informants described how every activity was planned and conducted in according to the present breathing status. For that reason a person-centered care approach [26] is to recommend when caring for individuals living with COPD and LTOT in order respect the individual's preferences and needs. Some of the informants were dependent on their relatives in order to manage in everyday life and they expressed that it could be a strenuous situation for the relative. Seamark and colleagues [27] interviewed patients with severe COPD and their caring relatives. The study showed that the relatives could hardly cope due to the burden of caring and all the roles they had to live up to. Berg [28] interviewed women taking care of their husbands with COPD and they described a lack of rest, recovery and support. They expressed feelings of being closed in and having lost their freedom due to the caring. Similar experiences of relatives have been described by Gabriel and colleagues [29]. It is interesting to notice that the informants in the current study had almost the same experiences regarding their situation in life as those mentioned by the caring relatives in previous research [27]–[29]. It could be hypothesized that caring or being cared for could result in similar situations in life. When being cared for at home, as several of the informants was, it is of the utmost importance to have good relationships to the relatives who in turn need to be supported and strengthened in their role as carers. In this respect, nurses and physicians caring for individuals with COPD and LTOT need to be aware of the informal caregiver's situation and offer them support in order to cope and possibilities to nurture their own interests.

Pulmonary rehabilitation is the non-pharmacological cornerstone in the treatment of individuals with COPD. There is good evidence that such rehabilitation leads to improved quality of life, reduction in symptoms, hospital admissions, depression and anxiety for instance [2]. In the current study some of the informants participated in rehabilitation and they seemed to value this treatment. Others described that they barely could move a few meters, which indicates that they probably would not be able to get to the rehabilitation although it most likely would be of benefit for them. Home-care provided by specially trained nurses could be one option to offer rehabilitation or self-care management for individuals living with COPD and LTOT who have difficulties leaving their homes. It could be argued that home-care could be costly but self-care management is known to reduce hospital admissions [17]. Therefore home-care could be cost effective, while contributing to an improved health related quality of life in individuals living with COPD and LTOT.

Methodological Considerations

One limitation with the current study may be that the data were collected some years ago. However, the experiences and the self-care strategies that the informants shared could still contribute to a deeper understanding for individuals living with COPD and LTOT that can be used when supporting patients with their self-care strate-

gies today. Another weakness may be that the findings are based on a rather small study group. More informants had perhaps contributed to a better accuracy. Therefore, it would have been advantageous to include more informants. However, the collected data were considered as sufficient to answer the aim of the study.

In a qualitative study reliability is considered in terms of the trustworthiness of the collected data and the validity of the interpretation and conclusions [30]. The trustworthiness of the method used is a requirement for several steps in the study, from interview to analysis [31]. All the interviews were performed by the first author, who has knowledge of this group of patients but was not involved in the care of these specific ones. The informants shared personal thoughts, reflections and experiences in a way that the researcher found astonishing. This was interpreted as confidence having been established. Not achieving depth in the interviews is a threat to the credibility of the findings [30].

The context is accounted for since it is important for the trustworthiness in a qualitative study [30]. Here the credibility determines whether the findings reflect the informant's true experiences or simply are a mirror of the investigator's subjective apprehension [30]. One option to establish trustworthiness is to tape all the interviews and transcribe them verbatim, which was adhered to in the current study and could be seen as a strength with the current study. The analysis was performed in cooperation between the first and the last author to ensure dependability and neutralize any possible subjective bias [30] [31]. To establish conformability, every step in the procedure of analysis is minutely described [30] and confirmed by quotations, which could be seen as a strength with the current study. The findings in this study serve to increase our knowledge and understanding of patients' experiences and their self-care strategies in everyday life when living with COPD and LTOT and therefore may be applicable to individuals living under similar circumstances [30] *i.e.* with the same severity of COPD.

5. Conclusion

The current study shows that living with COPD and LTOT led to experiences of constantly balancing between diminishing ability and increasing restrictions in everyday life. In order to preserve stability in everyday life when living in a spiral of a progressive lung disease dependent on oxygen therapy several hours a day, they had incorporated self-care strategies, which seemed to be a mixture of recommendations from health-care personnel and their own beliefs and experience. The self-care strategies were primarily aimed at preserving the present state of health, enabling physical activity and promoting a positive attitude. The current study suggests that individuals living with COPD and LTOT are encouraged to adopt self-care strategies directed towards maintaining stability with regard to their disease, physical capability and emotional reactions.

References

- [1] World Health Statistics (2008) World Health Organization. http://www.who.int/gho/publications/world_health_statistics/en/
- [2] Global Initiative for Chronic Obstructive Pulmonary Disease (GOLD) (2015) <http://www.goldcopd.com/>
- [3] O'Neill, E. (2002) Illness Representations and Coping of Women with Chronic Obstructive Pulmonary Disease: A Pilot Study. *Heart & Lung: The Journal of Critical Care*, **31**, 295-302. <http://dx.doi.org/10.1067/mhl.2002.123712>
- [4] Barnett, M. (2005) Chronic Obstructive Pulmonary Disease: A Phenomenological Study of Patients' Experiences. *Journal of Clinical Nursing*, **14**, 805-812. <http://dx.doi.org/10.1111/j.1365-2702.2005.01125.x>
- [5] Strang, S., Ekberg-Jansson, A. and Henoeh, I. (2013) Experience of Anxiety among Patients with Severe COPD—A Qualitative, In-Depth Interview Study. *Palliative & Supportive Care*, **6**, 1-8.
- [6] Stridsman, C., Lindberg, A. and Skär, L. (2014) Fatigue in Chronic Obstructive Pulmonary Disease: A Qualitative Study of People's Experiences. *Scandinavian Journal of Caring Sciences*, **28**, 130-138. <http://dx.doi.org/10.1111/scs.12033>
- [7] Jonsdottir, H. (1998) Life Patterns of People with Chronic Obstructive Pulmonary Disease: Isolation and Being Closed in. *Nursing Science Quarterly*, **11**, 160-166. <http://dx.doi.org/10.1177/089431849801100408>
- [8] Stridsman, C., Zingmark, K., Lindberg, A. and Skär, L. (2014) Creating a Balance between Breathing and Viability: Experiences of Well-Being When Living with Chronic Obstructive Pulmonary Disease. *Primary Health Care Research & Development*, **14**, 1-11.
- [9] Ek, K. and Ternstedt, B.M. (2008) Living with Chronic Obstructive Pulmonary Disease at the End of Life: A Phenomenological Study. *Journal of Advanced Nursing*, **62**, 470-478. <http://dx.doi.org/10.1111/j.1365-2648.2008.04611.x>
- [10] Medical Research Council Working Party (1981) Long-Term Domiciliary Oxygen Therapy in Chronic Hypoxic Cor-

- pulmonale Complicating Chronic Bronchitis and Emphysema. *Lancet*, **1**, 681-686.
- [11] Stoller, J.K., Panos, R.J., Krachman, S., Doherty, D.E. and Make, B. (2010) Long-Term Oxygen Treatment Trial Research Group. Oxygen Therapy for Patients with COPD: Current Evidence and the Long-Term Oxygen Treatment Trial. *Chest*, **138**, 179-187. <http://dx.doi.org/10.1378/chest.09-2555>
- [12] Ring, L. and Danielsson, E. (1997) Patients' Experiences of Long-Term Oxygen Therapy. *Journal of Advanced Nursing*, **26**, 337-344. <http://dx.doi.org/10.1046/j.1365-2648.1997.1997026337.x>
- [13] Ek, K., Sahlberg-Blom, E., Andershed, B. and Ternstedt, B.M. (2011) Struggling to Retain Living Space: Patients' Stories about Living with Advanced Chronic Obstructive Pulmonary Disease. *Journal of Advanced Nursing*, **67**, 1480-1490. <http://dx.doi.org/10.1111/j.1365-2648.2010.05604.x>
- [14] Eaton, T., Lewis, C., Young, P., Kennedy, Y., Garrett, J.E. and Kolbe, J. (2003) Long-Term Oxygen Therapy Improves Health-Related Quality of Life. *Respiratory Medicine*, **98**, 285-293. <http://dx.doi.org/10.1016/j.rmed.2003.10.008>
- [15] Riegel, B., Jaarsma, T. and Strömberg, A. (2012) A Middle-Range Theory of Self-Care of Chronic Illness. *Advances in Nursing Science*, **35**, 194-204. <http://dx.doi.org/10.1097/ANS.0b013e318261b1ba>
- [16] Renpenning, K. and Taylor, S. (2003) *Self Care Theory in Nursing: Selected Papers of Dorothea Orem*. Springer Publishing Company, Berlin.
- [17] Zwerink, M., Brusse-Keizer, M., van der Valk, P.D., Zielhuis, G.A., Monninkhof, E.M., van der Palen, J., Frith, P.A. and Effing, T. (2014) Self Management for Patients with Chronic Obstructive Pulmonary Disease. *Cochrane Database of Systematic Reviews*, No. 3, Article No. CD002990. <http://dx.doi.org/10.1002/14651858.cd002990.pub3>
- [18] Kaptein, A.A., Fischer, M.J. and Scharloo, M. (2014) Self-Management in Patients with COPD: Theoretical Context, Content, Outcomes, and Integration into Clinical Care. *International Journal of Chronic Obstructive Pulmonary Disease*, **9**, 907-917. <http://dx.doi.org/10.2147/COPD.S49622>
- [19] Graneheim, U.H. and Lundman, B. (2004) Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness. *Nurse Education Today*, **24**, 105-112. <http://dx.doi.org/10.1016/j.nedt.2003.10.001>
- [20] Effersoe, G.D. (2005) *Social sygdomsteori—Et situationelt perspektiv*. Forlaget, Samfundslitteratur, Frederiksberg.
- [21] Charmaz, K. (1983) Loss of Self: A Fundamental Form of Suffering in the Chronically ill. *Sociology of Health & Illness*, **5**, 168-197. <http://dx.doi.org/10.1111/1467-9566.ep10491512>
- [22] Earnest, M.A. (2002) Explaining Adherence to Supplemental Oxygen Therapy: The Patient's Perspective. *Journal of General Internal Medicine*, **17**, 749-755. <http://dx.doi.org/10.1046/j.1525-1497.2002.20218.x>
- [23] Cicutto, L., Brooks, D. and Henderson, K. (2004) Self-Care Issues from the Perspective of Individuals with Chronic Obstructive Pulmonary Disease. *Patient Education and Counseling*, **55**, 168-176. <http://dx.doi.org/10.1016/j.pec.2003.08.012>
- [24] Herbert, R. and Gregor, F. (1997) Quality of Life and Coping Strategies of Clients with COPD. *Rehabilitation Nursing*, **22**, 182-187. <http://dx.doi.org/10.1002/j.2048-7940.1997.tb02096.x>
- [25] Benzein, E. (1999) *Traces of Hope*. Doctoral Thesis, Umeå University, Umeå.
- [26] Cronenwett, L., Sherwood, G., Pohl, J., Barnsteiner, J., Moore, S., Sullivan, D.T., Ward, D. and Warren, J. (2009) Quality and Safety Education for Advanced Nursing Practice. *Nursing Outlook*, **57**, 338-348. <http://dx.doi.org/10.1016/j.outlook.2009.07.009>
- [27] Seamark, D.A., Blake, S.D. and Seamark, C.J. (2004) Living with Severe Chronic Obstructive Pulmonary Disease (COPD): Perceptions of Patients and Their Carers. *Palliative Medicine*, **18**, 619-625. <http://dx.doi.org/10.1191/0269216304pm928oa>
- [28] Berg, D. (2002) "The Hidden Client"—Women Caring for Husbands with COPD and Their Experiences of Quality of Life. *Journal of Clinical Nursing*, **11**, 613-621. <http://dx.doi.org/10.1046/j.1365-2702.2002.00651.x>
- [29] Gabriel, R., Figueiredo, D., Jácome, C., Cruz, J. and Marques, A. (2014) Day-to-Day Living with Severe Chronic Obstructive Pulmonary Disease: Towards a Family-Based Approach to the Illness Impacts. *Psychology & Health*, **29**, 967-983. <http://dx.doi.org/10.1080/08870446.2014.902458>
- [30] Lincoln, Y.S. and Guba, E.G. (1985) *Naturalistic Inquiry*. Sage Publications, Beverly Hills.
- [31] Kvale, S. (2008) *Doing Interviews*. SAGE Publications Ltd., Thousand Oaks.