

“This is What Lies Ahead”. Perspectives of Oxygen-Naïve COPD Patients on Long-Term Oxygen Use. A Qualitative Study

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Purpose: Oxygen is commonly prescribed to patients with severe COPD. However, little is known about the perspectives COPD patients, who do not yet use oxygen, have on this treatment.

Patients and Methods: A total of 14 oxygen-naïve patients with COPD Gold stages 3–4 and a high symptom burden participated in semi-structured interviews, in which their beliefs and expectations regarding oxygen therapy were explored. We used conventional content analysis to process our qualitative data.

Results: Four main themes were identified: seeking information, expected impact on quality of life, expected social impact and stigma, and last phase of life.

Conclusion: The message that home oxygen should be started, was regarded as bad news by most participants. The rationale behind the therapy and the way it is delivered were unknown to most participants. Some participants anticipated smoking-related stigma and social isolation. Misconceptions such as tank explosions, becoming housebound, full dependency on oxygen and an imminent death were common amongst interviewees. Clinicians should be aware of these fears and assumptions when communicating with patients on this subject.

Keywords: oxygen, palliative care, breathlessness, social stigma, chronic obstructive pulmonary disease

Introduction

Chronic obstructive pulmonary disease (COPD) is a highly prevalent, life-threatening lung disease. Due to its chronic course and its huge impact on quality of life, COPD is a major cause of morbidity and health care utilization.¹ Disease progression often leads to hypoxemia, rendering a significant proportion of patients eligible for long-term oxygen therapy (LTOT).^{2,3}

LTOT has been shown to increase survival in patients with COPD and severe hypoxemia,^{4,5} for whom its prescription has since been recommended by international guidelines.^{6,7} Moreover, in some studies on LTOT in hypoxemic COPD patients, exercise capacity and breathlessness improved and hospitalizations were reduced.^{8,9}

Despite these potential beneficial effects, patients with LTOT may experience major physical and psychosocial disadvantages. A recent systematic review on studies reporting perspectives of patients with advanced illnesses on LTOT for reducing breathlessness, identified numerous burdens.¹⁰ The handling of the equipment was cumbersome and hindered daily activities for some patients. Also, using LTOT led to significant emotional and psychological stress. Patients reported social isolation, safety concerns and an increased sense of vulnerability.

Understanding barriers, beliefs and expectations that patients may have when they hear that they are eligible for LTOT, is essential in providing adequate support and improving adherence. However, very little is known on the views and expectations of oxygen-naïve COPD patients. One qualitative study on perspectives of people experiencing breathlessness included six oxygen-naïve patients with various underlying conditions including COPD.¹¹ In this study, the important theme of anticipated stigma arose, as LTOT would make the illness visible. To our knowledge, all other studies on the psychosocial impact of LTOT included only oxygen users.^{10,12–15} However, oxygen-naïve patients (defined as patients who have never been prescribed LTOT) are unlikely to have been adequately informed about LTOT and have not perceived its effects in their home environment. Therefore, they may have different assumptions than oxygen users. Awareness of these potential assumptions is helpful for healthcare professionals in order to effectively communicate with patients on LTOT. Therefore, the aim of this qualitative study is to explore the perspectives of oxygen-naïve COPD patients on LTOT who may need this therapy in the future.

Materials and Methods

Study Design

Since literature on the subject is limited, a qualitative descriptive study design was used, with in-depth, semi-structured interviews. The qualitative approach of interpretive description was used to capture themes and patterns within the perspectives of oxygen-naïve COPD patients about LTOT.¹⁶ For analysis of the interviews, we chose to use inductive content analysis. This gave us the ability to gain insights into unique participant perspectives instead of using perceived categories.

The Medical Ethics Review Committee of the Amsterdam University Medical Centre concluded that this study was not subject to the Medical Research Involving Human Subjects Act. This research was conducted ethically in accordance with the World Medical Association Declaration of Helsinki. All participants gave informed consent which included publication of anonymized responses.

Participants

We chose to recruit oxygen-naïve patients with COPD Gold stages 3–4 and a high symptom burden (≥ 2 exacerbations yearly and/or modified Medical Research Council (mMRC)¹⁷ score ≥ 2), since they are most likely to be eligible for LTOT in the future. Consequently, these are the patients who are likely to have thoughts and expectations on this subject. Patients were recruited at the outpatient clinic of a large teaching hospital in an urban area in the Netherlands between November 2021 and May 2022. We purposefully sampled to recruit men and women with different ages, educational levels and smoking status. Exclusion criteria for participation were earlier use of LTOT and inability to participate (language barrier, cognitive impairment). Prior to each interview, written informed consent was obtained from each participant. Characteristics (age, gender, forced expiratory volume in one second (FEV1), smoking status and mMRC score) were collected at the time of the interview, and the most recent spirometry was used.

Interviews

A semi-structured interview schedule was developed from the existing literature on COPD patients' experiences on LTOT. The topics included perceived effect of LTOT on self-image, on daily life, on social life, on mobility, and whether LTOT provoked shame ([Table S1](#)). We estimated a sample of about 15 interviews would be needed until data saturation was reached.

Three researchers (KM, ED and EM), carried out the interviews at locations chosen by the patients. There was a doctor-patient relationship between KM and the participants, and no relationship between the participants and the other two interviewers. Each interview took approximately 60 minutes, were audio-recorded and transcribed verbatim.

Data Analysis

The first four interview transcripts were read by three researchers (KM, ED and EM) and coded line by line. Afterwards, codes were compared and discussed until consensus was reached. Since coding between all three researchers was

comparable, the remaining interviews were coded by one researcher (KM). The coding process was performed using Atlas.ti Scientific Software v.8 (<http://atlasti.com>; Atlas.ti Scientific Software Development GmbH, Berlin, Germany). When coding was complete, the codes were grouped into themes by KM. Finally, codes and themes were discussed with the other three researchers (EM, ED, YE) until agreement was reached.

Results

Fourteen patients were invited to participate (see Table 1). All agreed to participate, gave informed consent and were interviewed. Of note, one of the participants (P14) was mistakenly included despite having COPD GOLD 2. Since we deemed her interview valuable, she was not excluded.

During the analysis process, it was identified after fourteen interviews that themes were saturated and therefore no further participants were sought.

From the narratives, four themes were distilled: (1) seeking information, (2) expected impact on quality of life, (3) social impact and stigma, and (4) last phase of COPD.

Theme 1: Seeking Information

We distinguished three patterns in patients' need for information. Some patients wanted all available information on LTOT. Several stated that it was essential to involve their family caregivers; one patient stated that a good relationship between healthcare provider and patient was likely to increase receptiveness for LTOT. A second group of patients was ambivalent in their need for information. On the one hand, there was a desire for information; on the other hand, they expressed a fear of confrontation. The desire for information would depend on the symptoms they experienced.

Table 1 Characteristics of the Participants

Characteristic		N (%)
Age	55–59	1 (7%)
	60–64	2 (14%)
	65–69	4 (29%)
	70–74	4 (29%)
	75–79	1 (7%)
	80–84	2 (14%)
Gender	Female	8 (57%)
	Male	6 (43%)
FEV1, % of predicted	25–29%	4 (29%)
	30–34%	2 (14%)
	35–39%	2 (14%)
	40–44%	3 (21%)
	45–50%	2 (14%)
	>50%	1 (7%)
Education*	Lower secondary	3 (21%)
	Upper secondary	8 (57%)
	Bachelor	3 (21%)
mMRC	2	5 (36%)
	3	6 (43%)
	4	3 (21%)
Smoking status	Former	9 (64%)
	Current	5 (36%)

Note: *International Standard Classification of Education (ISCED) 2011.

Abbreviations: FEV1, forced expiratory volume in one second; mMRC, modified Medical Research Council Dyspnea Scale.

I am interested in my disease, what it does to other people and myself, and I try to find a certain balance. Let's say, at times when I am feeling not well, I am more interested in what the world has to offer for COPD, but that interest fades away once I am feeling better. (P10)

A third group of patients stated that they'd rather bury their head in the sand, since the whole concept of LTOT was too distressing for them, although they acknowledged that they might have to change their attitude later.

For someone with COPD, well let me speak for myself, sometimes there are things you just don't want to know about. It may sound strange, immature even, but I think I just don't want to know. I guess I'll see where the roads takes me. (P14)

When first asked on their views on LTOT, almost all patients responded with what they had seen in fellow patients. Seeing other patients with oxygen often had major impact; furthermore, patients often attempted to distill information from what they observed. This information was usually negative:

I saw that man, he suffered from COPD as well, changing in four or five months from a normal person to ... Well, he is three times as skinny as I am. That man is languishing. [...] I don't see any positivity. (P11)

I entered the physiotherapy clinic and saw a man coming in with an oxygen tank... I wanted to leave! This is what lies ahead. I was really shocked. And I thought, he can't even walk a bit on the treadmill. The whole time, I was completely fixated on that man. (P 12)

Theme 2: Expected Impact on Quality of Life

The majority of patients expected oxygen to relieve their breathlessness. Some patients expected LTOT to increase their mobility, other patients thought it might be a relief during breathlessness crises.

Walking distances, I think that's the only advantage. Just being able to walk longer distances, being able to go to the beach again. (P6)

Just having a little boost sometimes, when being very out of breath. (P4)

As opposed to an increased life-space mobility, many patients expected that LTOT would make their world smaller. They mentioned several practical reasons: going outside would be complicated, the system would be heavy, or the battery would run out of power.

You become fixated upon yourself, which can be tiresome. When using oxygen it shall be the same, continuously checking: 'Oh is there still enough', 'do I need to recharge it', 'are there parts that need to be replaced'. (P6)

Now I am free to go wherever, but then I will be dependent on equipment I have to carry along. (P11)

Several patients mentioned being connected to a tube as a major drawback. This appeared to have two underlying assumptions. First, the notion that their mobility would be defined by the length of the tube. Second, the idea that they would be "chained to something", not free.

Several patients pictured heavy metal tanks when they imagined what LTOT would be like. The idea of portable concentrators was far less threatening, but not all patients knew such portable systems existed. A possible reason, as stated by several patients, was that oxygen is "invisible" on the streets.

I've only seen people having an oxygen tank at home. None of them are leaving their houses anymore, their world shrinks. They let other people do things for them, although their car is parked right in front of their house. They don't come out anymore.(P11)

Besides portable concentrators, the idea of using LTOT "on demand" was also far less threatening than using it continuously.

I would not mind so much if I could use it shortly during the day. But when I hear about being connected to a tube for 16 hours, no that sounds awful to me. (P6)

When asked what would happen if the oxygen system would be near fire (eg from a cigarette), all participants stated that this would induce an explosion. This perceived explosion hazard led to feelings of anxiety in several participants.

Theme 3: Expected Social Impact and Stigma

Most patients expected that the start of LTOT would be a great shock to their loved ones. Some patients worried that their partner would turn into a caregiver. Furthermore, a negative impact on their own social life was expected by several patients. One reason mentioned was that the oxygen system would be too bothersome to take along. A second potential reason for patients was that they expected people to stop inviting them for outings if they were on LTOT. Several patients mentioned a third reason: they would be ashamed of the fact that they were dependent on oxygen, and consequently would see only their “inner circle”. Some patients assumed that the use of LTOT would make them feel disregarded by society. They also used terms such as “useless”, “a nobody”, “lamentable”. Linked to the shame is the feeling of guilt that some described. Apparently, they felt fully responsible for their illness and their need of LTOT.

Well, now you’ve got it. They might say that. And rightly so. And they would say: you had it coming, my friend. Yeah, you’re right, I’d say. (P8)

But I think there is a certain barrier for your appearance, with people looking at you and thinking: ‘wow, back off’. I don’t know how to explain this, it is a certain kind of shame I guess. (P11)

It triggers a lot of anger. I let this happen. I wish I hadn’t – why did I start smoking? (P12)

Theme 4: Last Phase of Life

Most patients assumed that prescription of LTOT would be triggered by a low level of functioning, not so much to correct hypoxemia. Most patients stated that LTOT was inevitable. Indeed, when they saw another patient on oxygen, they assumed it was their future too.

Several interviewees associated the start of LTOT with a shrinking world and with care dependency. For them, the prescription of LTOT would imply they had reached the terminal phase of their disease.

Mostly they crawl into their shells and stay in their houses in a very small circle. They build their whole world around them: a table, a seat or a sofa with a duvet on it, you know, that all turns into... Until it’s over. (P11)

It would scare me, because then you know you need a medical aid to stay alive. It is not just the idea of impairment, but also the feeling that you are reaching the end of life. (P10)

For me, I think it would be the last phase of being ill but still being able to recover. I think when the oxygen comes, then that’s over, that idea of recovering. (P11)

Many believed the oxygen could not be switched off anymore, rendering them dependent on it. This alleged dependency triggered feelings of anxiety. Indeed, most patients stated that “running out of oxygen” would make them very anxious. Also, it was common for patients to think that LTOT was addictive, and that the dosage would have to be increased in the future.

You start with one tablet, but at the moment I am taking around 12 of 13 tablets. It’s the same with oxygen. You get used to it and then you become, you know, addicted. (P 4)

Discussion

Our findings describe important assumptions and beliefs that patients with severe COPD may have on LTOT. The finding that they may relate LTOT to the (literal) end of life, has not been described before. Consequently, the idea of being eligible for oxygen should be regarded as very distressing for a subset of patients with COPD.

Furthermore, LTOT provoked several emotions that clinicians should be aware of. Firstly, some patients anticipated that they would feel guilty. In their opinion, they should have prevented the need for LTOT through self-management.

Feelings of guilt in COPD patients, due to self-inflicted disease associated with smoking habits, have been prescribed previously.^{18,19} However, the fact that prescription of LTOT might be a trigger for self-blame has not been described before.

Secondly, interviewees anticipated stigma provoked by LTOT. This finding is also in line with earlier studies.^{10,11,14} In a qualitative study on how patients with severe COPD experience daily life, patients perceived social blame because society judges their diagnosis to be self-inflicted.¹⁴ LTOT means the patient can no longer hide the disease, which may lead to anticipated stigma.¹¹ In the current study, several interviewees assumed they would become dependent on home care, would become housebound or would move to a nursing home. This complete disconnection from social life has been termed “social death”.²⁰ Characteristics of social death are a loss of social identity, a loss of social connectedness and losses associated with disintegration of the body.

A third emotion that was expressed by several patients, was anxiety. This anxiety was triggered by several misconceptions. Patients believed that after LTOT, there would be no other options to prolong their life. Furthermore, it was common for patients to assume LTOT would mean their life depended on a machine. Some feared addiction. Another fear that was expressed by the participants in our study, and also in previous literature, was the fear of explosion.²¹ Indeed, all patients in the current study stated that oxygen is an inflammable gas and a spark near the oxygen system would lead to an explosion. In reality, oxygen is not an inflammable gas, but makes other things ignite at a lower temperature. LTOT is associated with an increased risk of fire and burn injury, although the risk is probably very low in non-smokers.²² Therefore, awareness of fire risk is essential, but a fear for explosion is unrealistic.

Our findings are useful for the clinician who wants to bring up the subject of LTOT. Although some patients want all available information, others want to avoid the subject. Of note, the desire for information can be subject to change, depending on actual symptoms. When preparing a conversation about LTOT, health care professionals should verify if, and to which extent, a patient wants to be informed at that moment. A useful way to do this is the “ask-tell-ask – method” in which one first asks permission to share information.²³ After giving part of the information, one asks how the patient feels after receiving it, before more information is given. If the patient reacts strongly to the concept of LTOT, the clinician should explore which emotions or assumptions are at play. An example of a useful sentence in this context is: “Some patients with COPD are ashamed to be seen with oxygen. How is that for you?” According to our findings, it is helpful to ask patients if they know other patients on LTOT, and if so, how it affected them. Indeed, in our study most participants based their views on LTOT on what they had seen in fellow patients. This was also found by Wrench, who interviewed patients after initiation of LTOT and described how memories of others on oxygen formed a source of anxiety.¹⁵

Our data indicate that the start of LTOT affects thoughts patients have on their future. This underscores the notion that starting LTOT is an appropriate moment for advance care planning, as has been suggested previously.²⁴ The timing of advance care planning in COPD may be challenging, partly because patients may regard their disease as a “way of life”.²⁵ However, starting LTOT is a clear transition point within the disease trajectory that resonates with patients, and should serve as a “flag” for clinicians to consider tasks of palliative care such as advance care planning.

Another relevant finding of our study is the lack of knowledge on the purpose of LTOT. All participants believed that either breathlessness or low levels of functioning were the reason for healthcare providers to prescribe LTOT. The primary goal of the therapy, correcting hypoxemia in order to prolong life, was unclear to patients. This is in line with previous research that showed low levels of factual knowledge about oxygen use and a tendency to over-estimate potential benefits among patients with COPD.²⁶ Actively addressing misconceptions on the goal and effect of this therapy is important, since a lack of perceived benefit of LTOT is associated with non-adherence.²⁷

Not all participants expected LTOT to improve their levels of functioning. On the contrary, several feared that LTOT would limit their activities, even shrinking their world. This finding is in line with the meta-analysis by Kochovska et al, who found that active patients felt limited by LTOT, while patients with severe breathlessness felt greater freedom after initiating oxygen therapy.¹¹ Of note, most participants lacked knowledge on different forms of portable oxygen systems, which partly explains their fear of becoming housebound. When informing patients on LTOT, it is advisable to show a (picture of a) portable oxygen system, so their fear of being connected to a heavy tank may be taken away.

Strengths and Limitations

To our knowledge, this is the first study that focusses entirely on the perspectives of oxygen-naïve COPD patients on LTOT. Interviewing these patients has yielded new insights that had not become obvious from studies on oxygen users. The results may be easily implemented in communication training for health care providers who prescribe LTOT.

Our study has some limitations. One patient with COPD GOLD 2 has been included, despite our inclusion criterium of an FEV1 below 50%. Furthermore, the patients recruited for this study had a doctor-patient relationship with one of the researchers. This may have introduced a selection bias, with invited participants having stronger emotions about LTOT than the general population.

Conclusion

This study provides new insights in important topics that should be addressed during conversations on LTOT. First of all, clinicians should be aware of the possibility that they deliver bad news to patients. The rationale behind the therapy and the fact that it may be given with a portable system should be made clear. The clinician should assess whether patient and carer fear (smoking-related) stigma and social isolation. Misconceptions such as tank explosions, becoming housebound, full dependency on oxygen and an imminent death should be addressed. The initiation of LTOT presents a natural moment for advance care planning, because of the huge impact it may have on patients and carers.

Abbreviations

COPD, chronic obstructive pulmonary disease; FEV1, forced expiratory volume in one second; LTOT, long-term oxygen treatment; mMRC, modified Medical Research Council.

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Disclosure

Professor David Currow is a member of Advisory Board and paid consultant for Helsinn Pharmaceuticals, paid consultant and receive payment for intellectual property from Mayne Pharma International Pty Ltd, paid subcontractor for Nous Group Pty Ltd, paid Board member for icare Dust Diseases Care NSW, non-financial support from Chris O'Brien Lifehouse, non-financial support from IHMRI, during the conduct of the study. The authors report no other conflicts of interest in this work.

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