

Perception of Long-Term Oxygen Therapy for Chronic Lung Diseases May Affect Poor Adherence in Korea

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Abstract

Background: Long-term oxygen therapy (LTOT) improves the survival of patients with hypoxemia due to chronic respiratory diseases. The clinical outcomes of LTOT are strongly associated with patient adherence. To improve the adherence of patients, physicians have focused on the efficacy of LTOT. However, poor adherence may stem from patients' perceptions of LTOT. Herein we evaluated patients' perceptions of LTOT affecting adherence.

Methods: We conducted a cross-sectional survey study using descriptive, open, and closed-ended questionnaire. Patients using oxygen therapy (OT) or requiring it but avoiding OT responded to the questionnaires at three university hospitals.

Results: Seventy-nine patients responded to the questionnaires. The number of patients using home and portable OT was 69 (93%) and 37 (46.3%), respectively. Patients with good adherence were 22 (30.1%). Among patients with good adherence, 90.9% used oxygen according to physicians' prescriptions whereas only 37.3% of those with poor adherence followed physicians' prescriptions (p<0.01). The reasons for avoiding using home OT were fear of permanent use (50%), unwanted attention (40%), and lack of symptoms (40%). They avoided portable OT because of unwanted attention (39%), heaviness (31.7%), and lack of symptoms (21.6%).

Conclusion: Patients on LTOT had the perception of the misunderstanding the effects of OT and of psychosocial barriers to initiate or use LTOT. Considering these findings, health professionals need to provide effective education on the purpose of LTOT to improve patient adherence to OT and provide sufficient support for the management of psychosocial barriers in patients using LTOT.

Keywords: Chronic Respiratory Disease; Long-Term Oxygen Therapy; Perception

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Introduction

Chronic hypoxemia is a major complication of advanced chronic respiratory diseases, such as chronic obstructive lung disease (COPD), interstitial lung disease (ILD), and lung cancer. Chronic hypoxemia is associated with decreased quality of life, exercise capacity, and increased mortality^{1,2}. Long-term oxygen therapy (LTOT) has been recommended by international guidelines for decades at these stages of chronic lung disease^{3,4}.

Using LTOT for at least 15 hr/day improves survival in patients with chronic resting hypoxemia. Evidence of LTOT based on a randomized controlled trials in the early 1980s, the Medical Research Council (MRC) study, revealed a higher survival rate of 5 years after randomization in severely hypoxemic patients with COPD receiving supplemental oxygen therapy (OT) for >15 hr/day compared to the survival of those without OT⁵. In clinical practice, LTOT is commonly prescribed for other diseases such as ILD, cor pulmonale, cardiac disease, or neuromuscular disease using the same criteria used for COPD^{6,7}.

National and international guidelines recommend LTOT in the presence of appropriate criteria, which are defined as a resting partial pressure of oxygen in arterial blood (PaO₂) of 55 mm Hg or oxygen saturation (SaO₂) of 88% or a resting PaO₂ between 55 and 60 mm Hg with evidence of pulmonary hypertension, cor pulmonale, or polycythemia with a hematocrit value more than 55%. Patients with a peripheral oxygen saturation (SpO₂) below 88% at rest also qualify^{3,8}.

Patients with good compliance with LTOT tend to have good clinical outcomes, such as requiring fewer hospitalizations⁹. However, a significant number of patients discontinue treatment without reevaluation¹⁰⁻¹². Factors contributing to persistently poor compliance remain unclear. Despite several reports on the efficacy and compliance to LTOT in patients, most studies have focused on physicians' views of prescription patterns or medical efficacy^{8,9}. Only a few studies have considered the patients' perspectives, usually using text analysis of structured interviews^{13,14}. These studies showed that patients use oxygen as a tool for symptom management; however, the improvement in breathlessness by oxygen does not always meet expectations as perceived by patients. Factors affecting adherence may stem from patients' perceptions of OT. In this study, we investigated patients' perceptions of LTOT in a real-world clinical setting in Korea.

Materials and Methods

This cross-sectional survey study used descriptive open and closed-ended questionnaires. The survey was conducted at three university hospitals between December 1, 2017, and April 30, 2018. Patients older than 16 years with chronic hypoxemia due to chronic lung diseases who were currently using OT according to the LTOT criteria or who were required to use oxygen according to the LTOT criteria but avoided it, were included. Patients who did not meet the LTOT criteria and those who received OT after treatment for acute respiratory distress were excluded. The questionnaire was developed by five pulmonary specialists. The questionnaire consisted of 16 items, including five items on the timeframe of oxygen use and prescriptions of oxygen. The questionnaire included a benefit and adverse effects that patients experienced. There were also questions about patients' perception of avoidance of home oxygen and portable oxygen use. The Korean and English versions of the questionnaire are provided in the Appendices 1, 2.

1. Statistical analysis

All continuous variables were described as standard deviations (SDs), and categorical variables were reported as absolute numbers and percentages. Categorical values were analyzed using the chi-squared test or Fisher's exact test. In all comparisons, p-values <0.05 were considered statistically significant. All statistical analyses were performed using the SPSS version 25.0 (IBM Corporation, Armonk, NY, USA) for Windows (Microsoft Corporation, Redmond, WA, USA).

2. Ethical statement

This study was approved by the Institutional Review Board of the Inje University Paik Hospital, South Korea (IRB No.17-0177). All participants provided written informed consent before participating in the study. The study was conducted in accordance with the guidelines of the Declaration of Helsinki regarding the rights and dignity of participants.

Results

1. Baseline characteristics of patients with LTOT

Seventy-nine patients responded to the questionnaire on LTOT. Seventy-four patients used home or portable OT, 69 (93.2%) of whom used home OT and 37 (50%) used portable OT, respectively. Among patients using home OT, 32 (46.4%) used both OT (Figure 1). Among the five patients who used only portable OT, three had discontinued home OT and the remaining two patients had never used home OT. Among the five patients who needed to use LTOT but avoided using it, four had never used any OT, and one had previously used home OT. The mean±SD age was 69.8±8.9 years and 53 (67%) were men. The underlying respiratory diseases included COPD (n=41), ILD (n=22), bronchial asthma (n=10), tuberculosis destroyed lung disease (n=6), bronchiectasis (n=4), and others (n=4). Baseline forced expiratory volume in 1 second (FEV₁), forced vital capacity (FVC) and FEV₁/FVC of patients were 62.4%±21.1%,

 $45.3\%\pm20.1\%$, and $57.1\%\pm26.1\%$ of predicted. There were no significant differences between good and poor adherence groups. The details of the variables are shown in Table 1.

Figure 1. Oxygen devices of patients who currently use oxygen therapy. Results are described as numbers. The number of patients using home and portable long-term oxygen therapy (LTOT) was 69 and 37, respectively. five patients who used only portable LTOT, three had discontinued home LTOT and the remaining two patients had never used home LTOT.



2. Benefits and uncomfortable aspects of LTOT according to adherence

Among the 69 patients currently using home OT, only 20 showed good adherence to OT for more than 15 hr/day. Another 49 showed poor adherence to OT for less than 15 hr/day. In the poor adherence group, 28 patients had an OT less than 8 hr/day. Most patients in both the good and poor adherence groups answered that they felt better after using the LTOT. Sixty-nine patients used home oxygen; 59 (85.6%) reported that they experienced benefit of OT. The benefits in the good and poor adherence groups were relief from shortness of breath (85% vs. 83.7%, p=0.521), improvements in quality of life (30% vs. 30.6%, p=0.976), and increased activity after using oxygen (20% vs. 30.6%, p=0.364). The most uncomfortable aspects of using home OT were noise (60% vs. 48.9%, p=0.448), inconvenience of moving (45% vs. 48.9%, p=0.621), and local adverse effect such as of dry mouth (30% vs. 24.5%, p=0.694) (Table 2). In terms of portable OT, 33 (89.2%) considered portable OT was helpful. The uncomfortable aspects of portable OT in the good and poor adherence groups

Table 1. Baseline characteristics and underlying disease of patients

Variable	Total (n=79)	Good adherence* (n=22)	Poor adherence [†] (n=51)	p-value
Age, yr	69.8±8.9	70.4±8.0	68.5±9.7	0.442
Male sex	53 (67)	15 (68.2)	33 (64.7)	0.774
Smoking				0.928
Current smoker	7 (8.9)	2 (9.1)	5 (9.8)	
Ex smoker	32 (40.5)	11 (50.0)	21 (41.2)	
Never smoker	30 (38.0)	8 (36.4)	22 (43.1)	
Underlying respiratory diseases [‡]				
COPD	41 (51.9)	11 (50.0)	27 (52.9)	0.817
Interstitial lung disease	22 (27.8)	8 (36.4)	12 (23.5)	0.259
Bronchial asthma	10 (12.7)	2 (9.2)	8 (25.7)	0.452
Tuberculosis destroyed lung	6 (7.6)	1 (4.5)	4 (7.8)	0.609
Bronchiectasis	4 (5.1)	0	5 (9.8)	0.128
Others [§]	4 (5.1)	1 (4.5)	3 (5.9)	0.818
Pulmonary function				
FEV ₁ /FVC, %	57.1±26.12	58.5±22.2	57.2±28.0	0.844
FEV ₁ , %	45.3±20.1	45.8±21.1	46.2±19.7	0.931
FVC, %	62.4±21.1	58.0±23.1	64.2±20.9	0.266

Values are presented as mean±standard deviation or number (%). The Student t-test was used to compare continuous variable, and the chi-square test was used to compare categorical variables. A p<0.05 was taken to indicate significance. Among total 79 responder, six was excluded because of never using oxygen device (n=4) and using portable oxygen devise without answering the question (n=2). *Good adherence means that patients used oxygen therapy for more than 15 hr/day. [†]Poor adherence means that patients used oxygen therapy for less than 15 hr/day. [‡]Allow multiple responses. [§]Pneumoconiosis (n=3), post-pneumonectomy (n=1). COPD: chronic obstructive pulmonary disease; FEV₁: forced expiratory volume in 1 second; FVC: forced vital capacity.

Variable	Total (n=69)	Good adherence* (n=20)	Poor adherence [†] (n=49)	p-value
Was a home oxygen device helpful?				
Yes	59 (85.6)	17 (85.5)	42 (85.7)	0.986
No	3 (4.3)	1 (5)	2 (4.1)	
l don't know	7 (10.1)	2 (10)	5 (10.2)	
If it helped, what changes did you feel?				
Relief of shortness of breath	58 (84.1)	17 (85)	41 (83.7)	0.521
Improvement of quality of life	21 (30.4)	6 (30)	15 (30.6)	0.976
Feeling well	19 (27.5)	4 (20)	15 (30.6)	0.364
Increased activity time or amount	19 (27.5)	4 (20)	15 (30.6)	0.364
What are the disadvantages of using a device?				
Noisy	36 (52.2)	12 (60)	24 (48.9)	0.448
Inconvenient of moving	33 (47.8)	9 (45)	24 (48.9)	0.621
Nose hurts, dry mouth	18 (26.1)	6 (30)	12 (24.5)	0.694
Didn't feel it was effective	13 (18.9)	4 (20)	9 (18.4)	0.932
Associated expenses are burdensome	11 (15.9)	3 (15)	8 (16.3)	0.837

Table 2. The benefits and uncomfortable aspects of home LTOT according to adherence

Values are presented as number (%). The chi-square test was used to compare categorical variables. A p<0.05 was taken to indicate significance.

*Good adherence means that patients used oxygen therapy for more than 15 hr/day. [†]Poor adherence means that patients used oxygen therapy for less than 15 hr/day.

LTOT: long-term oxygen therapy.

were device-related complication: the associated heaviness (73.3% vs. 70%, p=0.829) and short battery life (80% vs. 45%, p=0.036) (Table 3).

3. How to use LTOT according to adherence

Among patients responded to the questionnaire on LTOT, 73 patients responded their timeframe of the oxygen. Patients with good adherence who used oxygen for more than 15 hr/day were 22 (30.1%). Most patients with good adherence underwent LTOT according to their physician's prescription (90.9%). Conversely, among 51 (69.9%) with poor adherence who used oxygen for less than 15 hr/day, only 37.3% used OT according to their physicians' prescription (p<0.01). A total of 34.7% of the patients used OT when they experienced dyspnea without conforming to the physician's prescription. Patients with poor adherence used OT 17.6% of used OT only during sleep and 9.8% used it when they did daily activities (Figure 2).

4. Reason for avoiding oxygen therapy

Patients responded their perceptions on avoiding OT. Among them, patients requiring home OT but avoiding it were 10. Five of them currently used only portable oxygen devices, four had never used any OT and one had used home oxygen devices but used no oxygen devices currently. The reasons for avoidance were fear of permanent use (n=5, 50%), unwanted attention (n=4, 40%), not feeling hypoxemia despite the presence of hypoxemia (n=4, 40%), and cost (n=3, 30%). Patients requiring portable OT but avoiding it were 41 (37 patients currently used only home OT, and four had never used any OT), The reasons for avoiding portable OT were: unwanted attention (n=16, 39%), heaviness during ambulation or moving (n=13, 31.7%), not feeling symptoms despite the presence of hypoxemia (n=8, 21.6%), and the fear of permanent use (n=5, 19.5%) (Figure 3). Perceptions of patients who were reluctant to use home or portable OT were in Supplementary Table S1.

Discussion

As insurance covers LTOT, its use continues to increase¹⁵. There is an increasing demand for the evaluation of LTOT with respect to intended medical effects as well as medical factors associated with compliance from the physicians' perspective. To our knowledge, this is the first study to provide patients' perspectives on LTOT in Korea. This study explored how patients feel and experience the LTOT in their lives. Table 3. The benefits and uncomfortable aspects of portable LTOT according to adherence

Variable	Total (n=37)	Good adherence* (n=15)	Poor adherence [†] (n=20)	p-value
Was a portable oxygen device helpful?				
Yes	33 (89.2)	15 (100)	17 (85)	
No	2 (5.4)	0	1 (5)	
l don't know	2 (5.4)	0	2 (10)	
If it helped, what changes did you feel?				
Relief of shortness of breath	33 (9.7)	15 (100)	18 (90)	0.521
Improvement of quality of life	15 (40.5)	3 (30.0)	7 (35)	0.240
Feeling well	11 (29.7)	7 (46.7)	8 (40)	0.898
Increased activity time or amount	10 (27.0)	5 (45.5)	6 (30)	1.000
What are the disadvantages of using a device?				
Heaviness	25 (70.3)	11 (73.3)	14 (70)	0.829
Shortness of battery	21 (56.6)	12 (80.0)	9 (45)	0.036 [‡]
Cost	10 (27.0)	6 (40.0)	4 (20)	0.195
Low flow	8 (21.6)	3 (20.0)	5 (25)	0.727
Difficult to use the devices	4 (10.8)	0	4 (20)	0.067
Noisy	2 (5.4)	0	2 (10)	0.207

Values are presented as number (%). The chi-square test was used to compare categorical variables. A p<0.05 was taken to indicate significance.

*Good adherence means that patients used oxygen therapy for more than 15 hr/day. [†]Poor adherence means that patients used oxygen therapy for less than 15 hr/day. [‡]p<0.05.

LTOT: long-term oxygen therapy.

Figure 2. How to use long-term oxygen therapy (LTOT) according to adherence. Results are described as number (%). Most patients with good adherence underwent LTOT according to their physician's prescription (90.9%). Conversely, among patients using oxygen therapy (OT) with poor adherence, only 37.3% used OT according to their physicians' prescription (p<0.01). *p<0.01. [†]Good compliance means when patients use OT for more than 15 hr/day. [‡]Poor compliance means when patients use OT for less than 15 hr/day.



LTOT improves survival in patients with severe hypoxemia who receive supplemental OT for more than 15 hr/day^{4,5}. Ringbaek et al.⁹ reported that home OT reduced the hospitalization rate from 92.7% to 63.8%. This benefit was particularly notable in the good compliant group. Previous domestic studies have exhibited good compliance more than 50% of patients who used OT for >15 hr/day and 15.4% who used OT for <8 hr/ day^{10,15,16}. Our study revealed poor adherence: only 30.1% of patients used OT for >15 hours, and 40.8% used OT for <8 hours. Since the study that reported 52% compliance was conducted before insurance coverage, these patients were considered to need OT because of physicians' decisions or their own complaints of dyspnea, even though they did not meet the current insurance criteria¹⁰. Another study that reported improvement compared with those reported by the former study included patients with diseases that did not meet the insurance criteria for OT¹⁶. Their underlying disease included advanced lung cancer. As a result, 72% of the patients died within 1 year and 92% died within 2 years. All these studies were conducted single-center setting. However, our multicenter study **Figure 3.** The reasons for avoiding oxygen therapy (OT). Results are described as number (%). Patients who needed to use home OT but avoided it consisted of five patients who currently used only portable oxygen devices, four patients who never used any OT, and one patient who had used home oxygen devices but used no oxygen devices currently. Patients who were reluctant to use portable OT who were consisted of 37 patients who currently used only home oxygen devices and four patients who never used any oxygen devices.



includes patients with chronic lung diseases who used oxygen according to the LTOT criteria. This suggests that compliance with OT may vary depending on the underlying disease and the region. In a recent study, oxygen prescriptions for patients with neuromuscular diseases were more common than oxygen prescriptions for patients with chronic respiratory disease according to National Health Insurance Service data in Korea¹⁷. The characteristics of OT were considered not only for patients with hypoxemia, but also for those with underlying diseases and their severity.

In previous domestic studies, none or 38% of patients used portable oxygen^{15,16}. Conversely, 46.4% of the respondents who used home oxygen also used portable oxygen. This finding may be attributed to the increased insurance coverage. In Korea, the National Health Insurance System extended insurance coverage to portable OT on January 1, 2017. As the economic burden decreased, the use of portable OT increased.

In our study, most patients felt that their symptoms had improved. More than 80% of the patients responded that their shortness of breath improved in both the good and poor adherence groups. The patients in both groups experienced local adverse effects related mouth and nose symptoms. However, no significant differences were observed between the good and poor adherence groups. In a recent domestic study, 36% patients voluntarily discontinued OT¹⁵. The cause of discontinuation was discomfort with OT, such as a dry mouth or nose. The number and types of local adverse effects were similar to those reported in previous studies, despite large differences in populations concerning underlying respiratory diseases, medical insurance coverage, and equipment types¹⁸⁻²⁰. These adverse effects are often neglected or left untreated by physicians⁸. The reason for persistent local adverse effects could be that the majority had not been treated or discussed with healthcare professional²⁰. Many commonly reported adverse effects can be treated, which could lead to a potentially positive effect on LTOT.

The most uncomfortable aspects of using portable oxygen were device-related complaints such as battery, noise, weight, and tube length. The longer patient used a portable oxygen device, the more uncomfortable they experienced that the short battery life. The battery was operated for approximately 3 hours depending on the flow at the pulse dose setting, and the recharge time was approximately 3 to 4 hours. The average noise was approximately 25 to 48 dB for home oxygen devices and about 42 to 48 dB for portable oxygen devices. Their average weight was approximately 3 kg, as measured using a portable oxygen device. The oxygen flow rate was approximately 1 to 3 L/min in a portable OT pulse dose setting. The tube lengths were 2.1 and 1.2 m for the home oxygen device and the portable device, respectively. Technical improvements were made to the oxygen devices, but the patients still experienced discomfort. While further development is necessary, inadequate guidance regarding the device may persist discomfort to use LTOT. Tubing length is a predictor of severe physical inactivity and time spent sitting²¹. Aguiar et al.¹⁸ reported that a tubing length of 30 m did not lower the fraction of inspired oxygen supplied and may provide greater freedom for patients to move around at home. Further studies on the appropriate standards for oxygen devices are needed.

In our study, 90% of the patients with good adherence responded that they used oxygen according to the physicians' prescription. However, among patients with poor compliance, only 36.7% conformed to physicians' prescriptions. Patients with poor adherence reported that they used oxygen only when they experienced dyspnea (34.7%) or when they slept or engaged in activities of daily living (18.4% and 10.2%, respectively). This finding emphasized that patients with poor adherence misunderstood the medical role of OT. As a medical treatment LTOT improves the survival of patients with severe hypoxemia. Instead of considering OT as a medical treatment and following physicians' prescriptions, patients with poor adherence used OT as a symptom reliever for complaints of dyspnea. A study on patients' perceptions of OT conducted in the United Kingdom, reported a common misunderstanding that oxygen was commonly administered to relieve dyspnea¹⁴. In a previous domestic study, the reason for voluntary cessation of OT was the relief of subjective symptoms¹⁵. In the same study, the objective parameters of dyspnea did not differ significantly between the enrolled groups, such as the MRC scale and visual analogue scale. Physicians have focused on objective parameters related to compliance^{8,9}. However, difference may not lay in objective medical effect but inpatients' subjective perceptions. Patients' perceptions of the purpose of OT could be the decisive factor in adherence.

In our study, the most common reason for avoiding home or portable oxygen was unwanted attention from onlookers. No significant differences were observed in terms of good or poor adherence. In one study, participants generally expressed that portable oxygen concentrators were helpful but received unwanted attention²². Williams et al.²³ noted that oxygen made their illness visible. Public use of OT seems to threaten the self-image of patients using both home and portable OTs^{24,25}. The largest study on the adverse effects associated to LTOT, conducted in 1998, reported that patients using LTOT felt negative self-conscious¹⁹. Regardless of whether compliance is good or poor, the use of LTOT tends to be associated with a psychological barrier of significant self-consciousness and a sense of social stigma that makes patients feel weak and sick²⁶. Consequently, negative self-image may be compromised, leading to embarrassment, worsening social isolation, and decreased patient adherence. Healthcare professionals provide sufficient support for the management of psychosocial barriers in patients using LTOT.

In our study, 50% of patients reported fear of dependency on OT as a reason for avoidance when requiring home OT, compared to 19.5% of patients with portable OT. Fear of dependency on OT was also related to reluctance among patients who had never used OT. One article reported that using oxygen was symbolic of a permanent decline in disease status or worsening of patients²⁷. Patients with severe COPD recognize initiation of OT as a key milestone in the disease trajectory and in declining health^{28,29}. LTOT is a marker of the terminal lung status and is often synonymous with disability and death. OT can demonstrate the recognition of disease severity, away from the unrealistic expectations about a better prognosis. The initial reaction to OT was fear of recognizing the severity of their disease and death. This psychosocial barrier may be the primary challenge in initiating LTOT in patients with advanced respiratory diseases.

Restriction of ambulation in daily living was another source of discomfort identified in our study. A previous study reported that the most prevalent adverse effects of LTOT are reduced mobility and physical activity²⁰. Several studies have reported that OT may be associated with low physical activity in daily life^{30,31}. Participants who used the LTOT show less independence in their activities of daily living^{21,32}. The ambulation restriction did not appear to restrict the movements imposed by the stationary device. The patients identified their weaknesses and felt trapped in their lungs. Restricted activities of daily living are associated with depression and poor health status²⁴. In some cases, depression gets intense and makes the individuals suicidal³³.

This study has several important implications. In clinical practice, to improve the adherence of patients, physicians have focused on objective factors or the medical efficacy of LTOT. However, most patients in both the good and poor adherence groups reported benefits and disadvantages associated OT. Both groups experienced improvement in their symptoms and revealed no evidence of deteriorating compliance with the use of oxygen due to adverse effect. We found that an important difference was patients' misunderstanding of the effects of OT. However, in a previous study on physicians' perspectives on home oxygen, physicians mainly emphasized the persistent use of home oxygen for >15 hours or not using too much oxygen³⁴. The patients' perceptions in our study highlight the need for health professionals to manage their perceptions of why they need oxygen. We found the psychosocial barriers that the patients in both good and poor adherence groups. Although it did not affect adherence, it may be a great obstacle to patient who are requiring oxygen or using it. Unwanted attention may interfere with initiation of portable OT, and fear of permanent use may make patients hesitate to initiate home OT. Restriction of daily activities will weigh on the patients with emotional burden. Identifying unrecognized perceptions and helping patients overcome negative perspectives could provide opportunities to improve initiation of OT and to explore what it is like living in a life-limiting condition. Sharing these experiences may help individuals make informed choices regarding advanced care plans for terminal chronic respiratory diseases.

1. Limitations

This study included patients who voluntarily agreed to complete the questionnaire. Therefore, only a small number of participants were enrolled. Nevertheless, our finding is meaningful. While previous studies on LTOT focused on patients who were currently using home or portable OT, the strength of this study is that it included patients who needed LTOT but avoided using it. Second, circumstances that might have influenced the survey results were excluded from the analysis. Underlying respiratory diseases, disease severity, performance status, equipment type, oxygen flow rate, and other confounding factors may have been hidden outside the scope of our survey. Further exploration of these factors may provide more information on patient compliance with LTOT. Despite these limitations, the results of this study can guide future studies aimed at managing and supporting negative perceptions as barriers to LTOT.

2. Conclusion

This study examined the perceptions of patients currently using or avoiding LTOT in Korea. Although the use of portable oxygen devices has increased since the insurance coverage was extended, patients' compliance remains poor. An important difference was the perception of the effects of OT between patients with good and poor compliance. The psychosocial barriers that the patients in both good and poor adherence groups may be a great obstacle to patient who are requiring oxygen or using it. Considering these findings, health professionals need to provide effective education on the purpose of LTOT to improve patient adherence to OT and provide sufficient support for the management of psychosocial barriers in patients using LTOT.

Authors' Contributions

Conceptualization: Lee H, Lee HK. Methodology: Yang JY, Lee HK. Formal analysis: Kim HJ, Lee H, Hong SM. Data curation: Lee H, Lee JH, Ra SW, Lee HY, Kim SH, Kim MY, Lee HK. Investigation: Kim HJ, Lee H. Writing - original draft preparation: Kim HJ, Lee H. Approval of final manuscript: all authors.

Conflicts of Interest

Seung Won Ra is an editorial board member of the journal, but he was not involved in the peer reviewer selection, evaluation, or decision process of this article. No other potential conflicts of interest relevant to this

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Supplementary Material

Supplementary material can be found in the journal homepage (http://www.e-trd.org).

Supplementary Table S1. The reasons for reluctance to use LTOT in all enrolled patients.

References

- Antonucci R, Berton E, Huertas A, Laveneziana P, Palange P. Exercise physiology in COPD. Monaldi Arch Chest Dis 2003;59:134-9.
- Zielinski J, MacNee W, Wedzicha J, Ambrosino N, Braghiroli A, Dolensky J, et al. Causes of death in patients with COPD and chronic respiratory failure. Monaldi Arch Chest Dis 1997;52:43-7.
- Global Initiative for Chronic Obstructive Lung Disease. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: 2019 report. GOLD; 2019 [cited 2023 Dec 2]. Available from: https://goldcopd.org/wp-content/uploads/2018/11/ GOLD-2019-v1.7-FINAL-14Nov2018-WMS.pdf.
- 4. Qaseem A, Wilt TJ, Weinberger SE, Hanania NA, Criner G, van der Molen T, et al. Diagnosis and management of stable chronic obstructive pulmonary disease: a clinical practice guideline update from the American College of Physicians, American College of Chest Physicians, American Thoracic Society, and European Respiratory Society. Ann Intern Med 2011;155:179-91.
- Long term domiciliary oxygen therapy in chronic hypoxic cor pulmonale complicating chronic bronchitis and emphysema: report of the Medical Research Council Working Party. Lancet 1981;1:681-6.
- Nocturnal Oxygen Therapy Trial Group. Continuous or nocturnal oxygen therapy in hypoxemic chronic obstructive lung disease: a clinical trial. Ann Intern Med 1980;93: 391-8.
- Jacobs SS, Krishnan JA, Lederer DJ, Ghazipura M, Hossain T, Tan AM, et al. Home oxygen therapy for adults with chronic lung disease: an official American Thoracic Society clinical practice guideline. Am J Respir Crit Care Med 2020;202:e121-41.
- Hardinge M, Annandale J, Bourne S, Cooper B, Evans A, Freeman D, et al. British Thoracic Society guidelines for home oxygen use in adults. Thorax 2015;70 Suppl 1:i1-43.
- 9. Ringbaek TJ, Viskum K, Lange P. Does long-term oxygen

therapy reduce hospitalisation in hypoxaemic chronic obstructive pulmonary disease? Eur Respir J 2002;20:38-42.

- Huh JW, Lee JY, Hong SB, Oh YM, Shim TS, Lim CM, et al. Long-term oxygen therapy in patients with chronic respiratory failure in one university hospital. Tuberc Respir Dis 2005;58:160-6.
- Lee YS, Cha SI, Han CD, Kim CH, Kim YJ, Park JY, et al. Clinical experience of long-term home oxygen therapy. Tuberc Respir Dis 1993;40:283-92.
- Oba Y, Salzman GA, Willsie SK. Reevaluation of continuous oxygen therapy after initial prescription in patients with chronic obstructive pulmonary disease. Respir Care 2000;45:401-6.
- 13. Bueno GH, Campos CJG, Turato ER, Paschoal IA, Valladao LS, Baltieri L, et al. Experiences in elderly people with chronic obstructive pulmonary disease in relation to the use of long-term home oxygen therapy: a qualitative study about feelings attributed to therapy. BMC Pulm Med 2022;22:96.
- Cullen DL, Stiffler D. Long-term oxygen therapy: review from the patients' perspective. Chron Respir Dis 2009; 6:141-7.
- 15. Koo HS, Song YJ, Lee SH, Lee YM, Kim HG, Park IN, et al. Clinical characteristics and adherence of patients who were prescribed home oxygen therapy due to chronic respiratory failure in one university hospital: survey after National Health Insurance Coverage. Tuberc Respir Dis 2009;66:192-7.
- 16. Kim KH, Park TY, Kim ES, Chung KB, Lee SM, Yim JJ, et al. Clinical features of patients on home oxygen therapy due to chronic respiratory failure at one university hospital. Korean J Intern Med 2012;27:311-6.
- Kim HI, Cho JH, Park SY, Lee YS, Chang Y, Choi WI, et al. Home mechanical ventilation use in South Korea based on National Health Insurance Service Data. Respir Care 2019;64:528-35.
- **18.** Aguiar C, Davidson J, Carvalho AK, lamonti VC, Cortopassi F, Nascimento OA, et al. Tubing length for long-term oxygen therapy. Respir Care 2015;60:179-82.
- Kampelmacher MJ, van Kestern RG, Alsbach GP, Melissant CF, Wynne HJ, Douze JM, et al. Characteristics and complaints of patients prescribed long-term oxygen therapy in the Netherlands. Respir Med 1998;92:70-5.
- 20. Bjorklund F, Ekstrom M. Adverse effects, smoking, alcohol consumption, and quality of life during long-term oxygen therapy: a nationwide study. Ann Am Thorac Soc 2022;19:1677-86.
- **21.** Cani KC, Matte DL, Silva IJ, Gulart AA, Karloh M, Mayer AF. Impact of home oxygen therapy on the level of phys-

ical activities in daily life in subjects with COPD. Respir Care 2019;64:1392-400.

- 22. Moller S, Ivarsson B, Nordstrom LA, Johansson A. LTOT patients' experience of a portable oxygen unit and health-related quality of life: a cross-sectional study. Healthcare (Basel) 2020;8:182.
- 23. Williams V, Bruton A, Ellis-Hill C, McPherson K. What really matters to patients living with chronic obstructive pulmonary disease?: an exploratory study. Chron Respir Dis 2007;4:77-85.
- 24. Ingadottir TS, Jonsdottir H. Technological dependency: the experience of using home ventilators and longterm oxygen therapy: patients' and families' perspective. Scand J Caring Sci 2006;20:18-25.
- 25. Doi Y. Psychosocial impact of the progress of chronic respiratory disease and long-term domiciliary oxygen therapy. Disabil Rehabil 2003;25:992-9.
- Earnest MA. Explaining adherence to supplemental oxygen therapy: the patient's perspective. J Gen Intern Med 2002;17:749-55.
- 27. Wrench C. How well do COPD patients with chronic respiratory failure and their carers adapt to using long-term oxygen at home? Prim Care Respir J 2012;21:109-10.
- 28. Landers A, Wiseman R, Pitama S, Beckert L. Patient perceptions of severe COPD and transitions towards death: a qualitative study identifying milestones and developing key opportunities. NPJ Prim Care Respir Med 2015;25:15043.
- **29.** Crockett AJ, Wilson A, Antic R, Greville H. ABS55: A qualitative study of patient perceptions of home oxygen therapy. Prim Care Respir J 2006;15:200.
- 30. Garcia-Aymerich J, Felez MA, Escarrabill J, Marrades RM, Morera J, Elosua R, et al. Physical activity and its determinants in severe chronic obstructive pulmonary disease. Med Sci Sports Exerc 2004;36:1667-73.
- **31.** Sandland CJ, Singh SJ, Curcio A, Jones PM, Morgan MD. A profile of daily activity in chronic obstructive pulmonary disease. J Cardiopulm Rehabil 2005;25:181-3.
- 32. Okubadejo AA, O'Shea L, Jones PW, Wedzicha JA. Home assessment of activities of daily living in patients with severe chronic obstructive pulmonary disease on longterm oxygen therapy. Eur Respir J 1997;10:1572-5.
- **33.** Barnett M. Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. J Clin Nurs 2005;14:805-12.
- **34.** Kim Y, Kim HI, Park JY, Hong JY, Kim JH, Min KH, et al. Korean physician prescription patterns for home oxygen therapy in chronic obstructive pulmonary disease patients. Korean J Intern Med 2022;37:119-26.

Appendix 1. The questionnaire: full English version

<Questions1-9: Questions about home oxygen therapy devices>

1. Have you ever used a home oxygen therapy device?

1) Yes (Please answer questions 3–9)

2) No (Please answer question 2)

2. Are you willing to use an oxygen therapy device if your doctor recommends it?

1) I will use it if the doctor says it is necessary. (Please, answer question 9)

2) I will not use it even though the doctor says I need it. (Please, answer question 9)

3. Are you currently using a home oxygen therapy device (stationary)?

1) Yes, I am currently using it.

2) I've used it before but I am not currently using it.

4. Please answer how you use oxygen therapy (multiple answers)

1) I use oxygen therapy as prescribed by my doctor, even if I am not short of breath

- 2) I use it when I feel short of breath.
- 3) I use it only during sleep.
- 4) I use it when doing activities (washing, bathroom, eating).
- 5) I use it when traveling (only in a car or vehicle).
- 6) Others (Please specify:)

5. How many hours per day do you use oxygen on average? (Please answer each item below)

5-1. How many hours per day do you use oxygen at rest?

- 1) 0–2 hours 2) 2–4 hours
- 3) 4–8 hours
- 4) 8–12 hours
- 5) Over 12 hours

5-2 How many hours per day do you use oxygen while sleeping?

- 1) 0-4 hours
- 2) 4–8 hours
- 3) Over 8 hours

5-3. How many hours per day do you use oxygen during exercise?

- 1) 0-2 hours
- 2) 2-4 hours
- 3) 4-8 hours
- 4) Over 8 hours

* Total hours(calculated):

- 6. What are the disadvantages of using an oxygen therapy device? (Multiple answers are possible) Please list up to 3, in order of priority.
- 1) Noisy. (Noise problem)
- 2) Associated expenses (rent fee, electricity, etc.) are burdensome.
- 3) I didn't feel it was effective (It doesn't seem to help).
- 4) It is inconvenient to move with the oxygen device plugged in.

5) My nose hurts, becomes dry, or I catch a cold easily because of the oxygen line 6) Others ()

7. Was a home oxygen device helpful for your activities and breathing?

- 1) It was helpful after using it. (Please answerquestions7-1)
- 2) It helped a little after using it. (Please answer question 8)
- 3) I do not know. (Please answer question 8)

7-1. If it helped, what changes did you feel? (Multiple answers are possible)

1) Relief of shortness of breath

- 2) Feeling that way, the changes
- 3) Improvement of quality of life
- 4) Increased activity time or amount

5) Others (Please specify:

8. Please write what you hope to be supplemented or improved about using a home oxygen device.

(

)

9. What is the reason for your reluctance to use oxygen therapy when you are recommended or assumed to be recommended by your doctor? (Multiple answers are possible)

Please list up to 3 in order of priority.

- 1) What other people will think of me (It seems like they look at me strangely or keep staring at me).
- 2) I don't feel I need to use it (I'm short of breath).
- 3) I am afraid that if I use it once, I will continue to have to use it.

)

- 4) Oxygen seems to be harmful to the body (I'm afraid I'll get addicted).
- 5) It seems costly.
- 6) Others (Please specify:)

<Question10-16: Questions about portable oxygen therapy devices>

10. Has a doctor ever recommended that you use a portable oxygen therapy device?

1) Yes

2) No

11. If your doctor recommends using a portable oxygen device, are you willing to use it?

1) I will use it if the doctor says it is necessary. (Please answer question 16)

- 2) I will not use it, even if the doctor says it is necessary. (Please answer question 16)
- 3) I do not know. (End of the survey)

12. Have you ever used a portable oxygen device?

- 1) Yes, I am currently using it (Please answer question 4)
- 2) Yes, I have used it in the past. (Please answer question 4)

3) No, I've never used it.

13. Did using a portable oxygen device help you to be active?

- 1) Using it was helpful for activities after wards.
- 2) It didn't help much after using it.

3) I do not know.

14. Please select problems encountered when using a portable oxygen device. (Multiple answers are possible) Please list up to 3 in order of priority.

1) It is heavy and difficult to carry.

2) It doesn't seem to be providing enough oxygen.

3) The charge does not last long. (It cuts off while moving.)

4) It is costly.

5) Machine operation is complex.

6) Others (Please specify:)

15. Please write what you hope to be supplemented or improved about using a portable oxygen device.

- 16. What is the reason for your reluctance to use portable oxygen therapy when you are recommended or assumed to be recommended by your doctor? (Multiple answers are possible). Please list up to 3 in order of priority.
- 1) What other people would think of me (It seems like they look at me strangely or keep staring at me.)
- 2) I don't need to use it (I'm short of breath).
- 3) I am afraid that if I use it once, I will continue to have to use it.

)

4) Oxygen seems to be harmful to the body (I'm afraid I'll get addicted).

5) It seems costly.

- 6) Portable oxygen devices are heavy.
- 7) After re-charging, the charge of the oxygen device only lasts a short time.

8) Others (Please specify:

Appendix 2. The questionnaire: full Korean version

〈문항 1-9 고정식 산소 발생기 관련 설문〉
1. 고정식 산소 발생기를 사용해 본 적이 있으십니까?
1) 예 (3-9 번 문항에 답변해 주세요)
2) 아니오 (2번 문항에 답변해 주세요)

2. 의사로부터 산소발생기 사용을 권유 받은 경우 사용할 의향이 있습니까?
1) 의사가 필요하다고 하면 사용하겠다. (9번 문항에 답변해 주세요)
2) 필요하다고 해도 사용하지 않겠다. (9번 문항에 답변해 주세요)

3. 현재 가정용 산소 발생기(고정식)를 사용 중입니까?
1) 네 현재 사용 중입니다.
2) 이전에 사용해 본 적이 있지만 현재는 사용하지 않습니다.

4. 산소를 사용하는 방법에 대해 답변 주세요(복수응답 가능)
1) 숨이 차지 않아도 의사 처방대로 산소를 사용한다.
2) 숨이 차다고 느낄 때 사용한다.
3) 수면 중(잠잘 때)에만 사용한다.
4) 활동을 할 때(세면, 화장실, 식사)시 적용한다.
5) 이동 시(차량이나 운송수단 내에서만)사용한다.
6) 기타 (이유를 구체적으로 기술하여 주세요:)

5. 하루 평균 산소 사용시간은 하루 중 몇시간 정도입니까? (아래 항목별로 답해 주세요)

5-1. 안정 시 산소사용 시간은 하루 중 몇시간 정도입니까?

1) 0-2시간 2) 2-4시간 3) 4-8시간 4) 8-12시간 5) 12시간 이상

5-2 수면 시 산소사용 시간은 하루 중 몇 시간 정도입니까?

- 1) 0-4 시간 2) 4-8시간
- 3) 8시간 이상

5-3. 운동 시 산소사용 시간은 하루 중 몇시간 정도입니까?

1) 0-2시간 2) 2-4시간 3) 4-8시간 4) 8시간 이상

*총사용시간(합산):

6. 산소발생기를 사용하면서 불편한 점은? (한 개 이상 응답가능) 1,2,3 순으로 적어주세요

시끄럽다. (소음문제)
 비용 (임대료 전기세 등)이 부담된다.
 효과를 못 느꼈다. (도움이 되지 않는 것 같다.)
 산소를 꽂은 상태로 이동하기가 불편하다.

5) 산소줄 때문에 코가 아프거나, 건조하고 코감기가 잘 걸린다. 6) 기타 ()

7. 고정식 산소발생기를 사용 후 활동 및 호흡에 도움이 되었습니까? 1) 사용 후 도움이 되었다. (7-1번에 답해 주세요) 2) 사용 후 별 도움이 안 되었다. (8번에 답해 주세요) 3) 잘 모르겠다. (8번에 답해 주세요)

7-1. 도움이 되었다면 체감하는 변화는 무엇입니까? (복수응답가능)

1) 호흡곤란의 완화 2) 기분 상의 변화 3) 삶의 질 향상

4) 활동 시간 혹은 활동량의 증가

5) 기타()

8. 고정식 산소발생기 사용과 관련하여 보완이나 개선되었으면 하는 점을 적어주십시오.)

(

9. 의사로부터 산소발생기 사용을 권유 받았거나 권유 받았다고 가정했을 대 산소 사용을 꺼리는 이유는 무엇입니까? (한 개 이상 응답가능) 1.2.3 순으로 적어주세요. 1) 다른 사람의 시선 (이상하게 불 것 같다. 자꾸 쳐다볼 것만 같다.) 2) 사용 필요성을 느끼지 못해서 (숨이 안 차다.) 3) 한 번 쓰면 계속 써야 될까 겁난다. 4) 산소가 몸에 해로운 것 같다. (중독될까 겁난다.)

5) 비용이 많이 들 것 같다. 6) 기타 ()

〈문항 10-16 이동식 산소발생기 관련 설문〉 10. 의사로부터 이동식 산소발생기 사용을 권유 받은 적이 있습니까? 1) 예 2) 아니요

11. 의사로부터 이동식 산소발생기 사용을 권유 받은 경우, 사용할 의향이 있습니까? 1) 의사가 필요하다고 하면 사용하겠다. (16번 문항에 답변해 주세요) 2) 필요하다고 해도 사용하지 않겠다. (16번 문항에 답변해 주세요) 3) 잘 모르겠다. (설문종료)

12. 이동용 산소발생기를 사용해 본적이 있습니까? 1) 네 현재 사용 중입니다. (4번 문항에 답변해 주세요) 2) 네, 과거에 사용해 본 적이 있습니다. (4번 문항에 답변해 주세요)

3) 아니요, 사용해 본 적은 없습니다.

13. 이동용 산소발생기를 사용 후 활동하는데 도움이 되었습니까? 1) 사용 후 활동하는데 도움이 되었다. 2) 사용 후 별 도움이 안 되었다. 3) 잘 모르겠다.

14. 이동용 산소발생기 사용 시 문제점을 골라주십시오. (한 개 이상 응답가능) 1,2,3 순으로 적어 주세요.

1) 무거워서 들고 다니기 어렵다. 2) 산소가 잘 안 들어오는 것 같다. 3) 충전시간이 너무 짧다. (이동중에 끊긴다.) 4) 가격이 비싸다.

5) 기계 조작이 어렵다. 6) 기타 ()

15. 이동식 산소발생기 사용과 관련하여 보완이나 개선되었으면 하는 점을 적어주십시오.

16. 의사로부터 이동식 산소발생기 사용을 권유 받았거나 권유 받았다고 가정했을 때 산소 사용을 꺼리는 이유는 무엇입니까? (한 개 이상 응답가능) 1,2,3,4, 순으로 적어 주세요.
1) 다른 사람의 시선 (이상하게 볼 것 같다, 자꾸 쳐다볼 것만 같다.)
2) 사용 필요성을 느끼지 못해서 (움직일 때 숨이 안 차다.)
3) 한 번 쓰면 계속 써야 될까 겁난다.

4) 산소가 몸에 해로운 것 같다. (중독될까 겁난다.)

5) 비용이 많이 들 것 같다.

6) 이동용 산소 발생기가 무겁다.

)

7) 일회충전 후 산소 발생기 사용시간이 짧은 점.

8) 기타 (