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# A telephone-based survey of current trends, habits and beliefs in patients receiving portable oxygen therapy in Madrid, Spain

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ABSTRACT Portable oxygen therapy is a major challenge for patients and clinicians. Additionally, the available evidence on this subject is poor considering that only a few studies have been published and the results have not been encouraging. We explored the current trends, habits and beliefs among patients receiving portable oxygen therapy in a geographical area of Madrid, Spain (4 051 862 inhabitants).

A telephone-based survey was conducted among patients selected from a database who were undergoing portable oxygen therapy.

The number of patients on home respiratory therapies on December 31, 2017 was 81 559 (prevalence 2013.30 per 100 000 inhabitants). A total of 19 492 patients were on home oxygen therapy (HOT) (prevalence 481.16 per 100 000 inhabitants). Of these, 4015 patients (20% of the total of patients on HOT) received ambulatory oxygen therapy. In the analysed period, 1942 patients were selected (57.31% male and 42.69% female). The mean±SD age was 73.89±11.67 years. Most of patients had portable oxygen concentrators (99.59%). The survey was completed by 1777 patients. Most of patients thought they had been prescribed HOT for respiratory failure. 55% of the participants surveyed reported having carried out a walking test with oxygen to know the amount of oxygen they needed. 71% of the participants reported leaving the home for between 1 and 3 h a day. Most of them were carrying portable devices in a wheeled cart (51.94%).

Our study data obtained from a large sample of oxygen-dependent individuals provide valuable information regarding domiciliary and portable oxygen usage in Madrid.

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**A telephone survey was conducted in patients undergoing portable oxygen therapy. Data from a large sample of patients show us that they have a good training in ambulatory oxygen use.** http://bit.ly/2Z6mP94

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## Introduction

Continuous home oxygen therapy (HOT) is the treatment of choice for patients with chronic obstructive pulmonary disease (COPD) and chronic respiratory insufficiency. By extension, it is also indicated in respiratory failure due to other diseases, such as interstitial pulmonary diseases [1]. In the Fifth Oxygen Consensus Conference held in Denver (CO, USA) in 1995 [2], portable oxygen was considered the standard of care for patients who were able to be active both inside and outside the home, beyond the limits of a stationary system. However, a few years later, a Cochrane Database systematic review [3] showed that evidence available to date did not allow any firm conclusions to be drawn concerning the effectiveness of portable domiciliary oxygen therapy in patients with COPD. Since then, only few studies on ambulatory oxygen have been published and the results have not been encouraging [4–6]. In addition to the lack of effectiveness, other problems with portable oxygen therapy, such as poor adherence, its indiscriminate use or the number of prescriptions out of indication, have been reported [7]. To better understand the current situation of patients receiving oxygen in our geographical area, we conducted a telephone-based survey of current trends, habits and beliefs in patients receiving portable oxygen therapy in Madrid, Spain.

## Methods

A telephone-based survey was conducted in patients undergoing portable oxygen therapy that were registered in the database of the local homecare provider Oximesa Nippon Gases (Madrid). This company is the home respiratory care company responsible for the provision of domiciliary respiratory therapies in a geographical area of the Community of Madrid that gives coverage to a population of 4 051 862 inhabitants (figure 1). In this area, all patients receiving domiciliary oxygen therapy, noninvasive

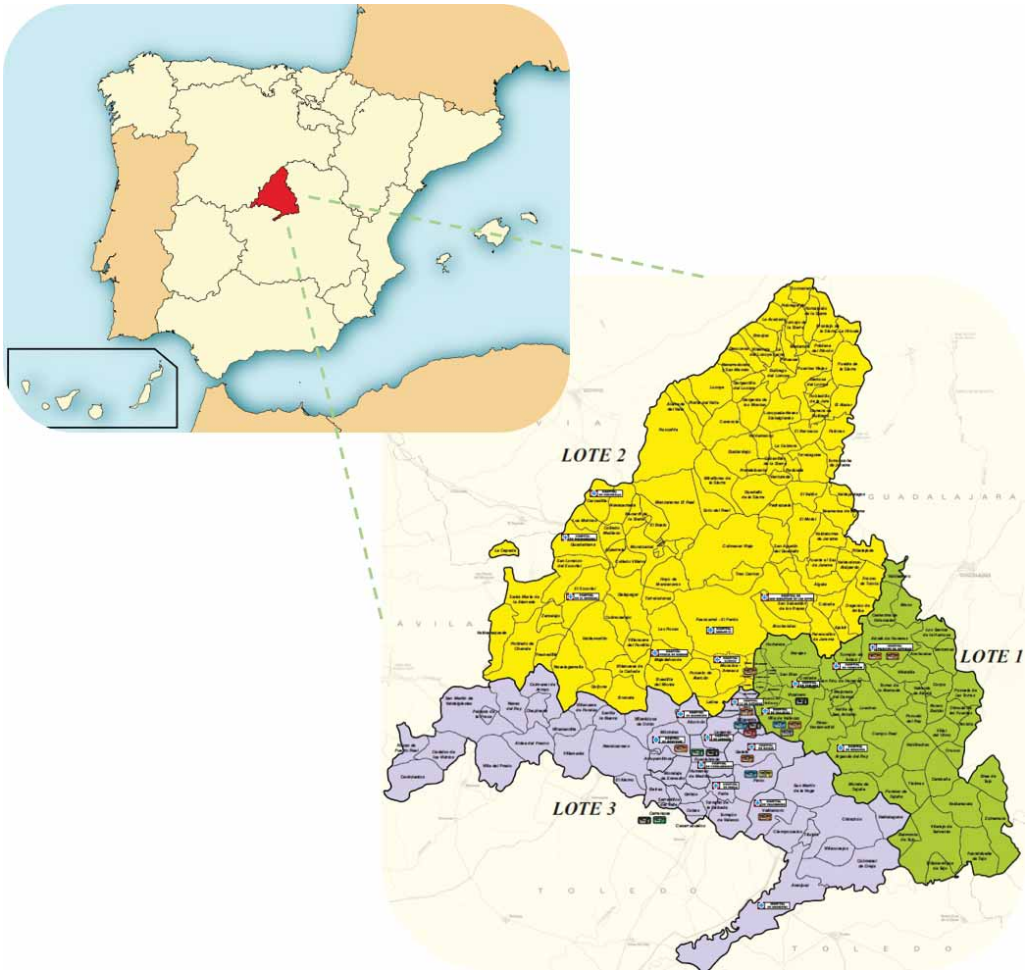


FIGURE 1 Map of the Community of Madrid. The geographical areas under the responsibility of the home care provider Oximesa Nippon Gases are the yellow zone marked as Lote 2 and the purple zone marked as Lote 3. It can be seen that Oximesa Nippon Gases is responsible for the respiratory homecare of ~70% of the population of Madrid.

ventilation, nasal continuous positive airway pressure and other home respiratory therapies, are included in a database that is shared with prescribing physicians. Half of patients on portable oxygen therapy recorded in the database were selected by simple random sampling (99% confidence level and 2% margin of error). Patients included in the database had an associated number to ensure data anonymisation. Random selection of participants was facilitated by Excel Random Sample Software (Microsoft Corp, Redmond, WA, USA). Patients with active cancer and those in whom oxygen was indicated for palliative purposes were excluded. The survey was carried out by the homecare provider healthcare team and patients were asked for their collaboration. Participants were assured of their anonymity and they gave their consent to be included in the study. The survey consisted of four questions about demographic characteristics of the participants, and 22 questions about the life habits related to portable oxygen therapy, the satisfaction of patients with this therapy and the quality of the service provided by the company (supplementary material). The collected data were analysed by mean and standard deviation, and by frequency distribution of qualitative variables. The Chi-squared test was used to compare percentages. The study was approved by the Ethics Committee of University Hospital Puerta de Hierro (Madrid).

## Results

The population to which the homecare provider gave domiciliary coverage in the period of the study (June to December 2017) was 4 051 862 inhabitants. The number of patients with home respiratory therapies on December 31, 2017 was 81 559 (prevalence 2013.30 per 100 000 inhabitants). Of these, 19 492 patients were on HOT (prevalence 481.16 per 100 000 inhabitants); 55 527 patients were receiving treatment for sleep apnoea; 3019 patients, home mechanical ventilation; and 3521 patients, domiciliary aerosol therapy. A total of 4015 patients (20% of the total of patients on HOT) received portable oxygen therapy (portable oxygen concentrators (POCs) or liquid oxygen). Patients who had POC also had stationary concentrators to perform HOT inside the house and at night (figure 2). No patients were prescribed only portable oxygen therapy.

During the study period, 1942 patients on portable oxygen therapy were selected (57.31% male and 42.69% female). The mean±SD age was 73.89±11.67 years. Portable oxygen therapy was performed with POCs in 1934 (99.59%) patients and only in eight (0.41%) with a liquid oxygen stroller. The survey was completed by 1777 patients. There were 165 patients who were not contactable by telephone or declined their participation in the study. The diagnoses recorded in the database were COPD (71%), interstitial lung diseases (ILDs) (10%), chronic heart failure (11%), lung cancer (5%) and others (3%). The majority of patients (87.11%, 1548 patients) lived with relatives, 10.92% (194 patients) lived alone and 1.97% (35 patients) were institutionalised. The main caregivers were family members (75.57%); 18.01% (320 patients)

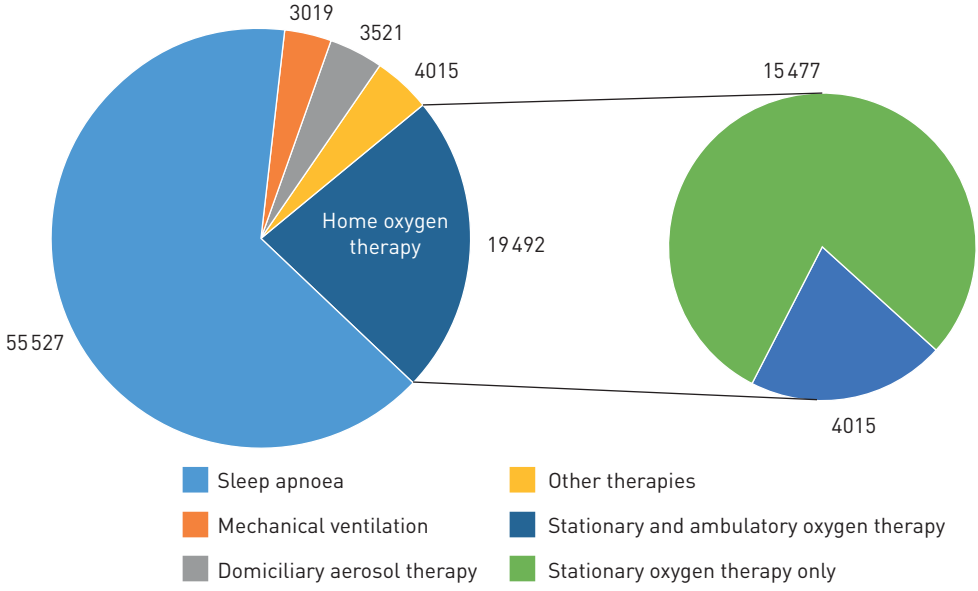


FIGURE 2 Distribution of patients receiving home respiratory therapies from Oximesa Nippon Sanso in the Community of Madrid on December 31, 2017. A total of 19 492 patients were on home oxygen therapy. Of these, 4015 patients (20% of the total of patients on home oxygen therapy) received ambulatory oxygen therapy (portable oxygen concentrators or liquid oxygen).

had a non-family caregiver for several hours a day and 6.42% (114 patients) for 24 h a day. 22% of patients had access to their home only by stairs.

43% of patients thought they had been prescribed HOT for respiratory failure, 52.79% because they needed it for their respiratory disease, 3.94% for dyspnoea, and 0.73% did not know the reason. In relation to portable oxygen, 59.65% of patients thought that they had been referred because a reduction of oxygen saturation on effort or physical activity, 31.80% because they needed oxygen all day, 8.33% because the appearance of dyspnoea while exercising and 0.23% did not know the reason. The 83.06% of patients reported that they used oxygen during the day and night, while 7.99% used it only during the night and 8.95% only during the day.

81.04% (1440 patients) reported having carried out a standardised 6-min walk test (6MWT) before starting the oxygen therapy. 27.24% (484 patients) reported having carried out a walking test with a POC to know the amount of oxygen they needed, while 27.69% (492 patients) performed the test receiving oxygen from the wall outlet of the hospital. 801 (45.07%) patients reported not having performed any test to identify their oxygen needs. Of the 976 (54.93%) patients who performed some type of walking test with oxygen, the exact prescription of oxygen flow expressed in litres per minute only was recorded among 317 (17.83%) patients, namely <3 $L \cdot min^{-1}$ in 258 (14.51%) patients and >3 $L \cdot min^{-1}$ in 59 (3.32%) patients. In the remaining 659 patients, the POC settings were recorded (all patients showed a POC prescription at position 3–5). The POC equipment used by patients were Inogen One (Inogen, Goleta, CA, USA), Eclipse 3 (Sequal, San Diego, CA, USA) and EverGo (Philips Respironics, Murrysville, PA, USA).

18% (313 patients) were at home for >3 h a day, 70.51% (1253 patients) between 1 and 3 h a day, and 11.87% (211 patients) for <1 h a day. 85% of patients who reported daily life activities outside home (one or more times a day) used oxygen when they left their homes, while 15% used it only in some occasions. There were ~30% patients with a daily use of portable oxygen despite leaving the home five or fewer times a week.

When activity outside home was evaluated, we found that 58% of patients who performed a walking test before being prescribed portable oxygen and 57% who performed the test with oxygen left their home one or more times a week. By other hand, only 40% of patients who did not do a basal walking test and the 33% of patients who did not do the walking test on oxygen, leave home one or more times a week.

39% (701) of patients admit using portable oxygen to go for a walk, 31.63% (562) to visit family and friends, 17.05% (303) to go shopping and 87% (211) to go to the doctor, clinic or hospital. 34% (596) of patients carry the portable devices on their shoulders, hung up; the 51.94% (923) carry it in a wheeled cart and 14.52% (258) are transported by a family member or caregiver. The 65.40% (1204) of patients complain of having to climb stairs with portable oxygen. The duration of the battery seems sufficient to 18.40% of patients (327), insufficient to 56.84% (1010) and very insufficient to 24.76% (440).

Patients valued that portable oxygen allows them to leave home experiencing less dyspnoea (78.90%), that it gives them peace of mind to leave home (66.01%) and that it allows them to move around their house without using extension sets (15.19%), and some patients considered portable oxygen devices easy to use (7.88%). However, the main reasons patients did not like portable oxygen devices were their excessive weight (83.74%), that they are difficult to use (32.25%), that the equipment makes too much noise (13.62%) and that they do not like to be seen receiving oxygen outside the home (28.14%) (figure 3).

Table 1 shows an overview of the results of the main questions on life habits related to portable oxygen therapy.

## Discussion

This study provides important information about individuals on portable oxygen therapy obtained from a large sample of patients on HOT in a geographical area of 4 051 862 inhabitants in the Community of Madrid. We have found a HOT prevalence of 481.16 per 100 000 inhabitants. Previous publications report great variability in the HOT prevalence among countries, even within the same country, the largest being in the USA (241 per 100 000) [8]. In 2007, data from the British Home Oxygen Database [9] showed us that HOT prevalence remained constant at about 11–12 per 100 000 inhabitants until the age of 45 years, beginning to increase from this age until reaching a peak of 880 per 100 000 inhabitants in those >80 years. More recently, an average prevalence of 264 per 100 000 inhabitants in Spain has been reported [10]. Our findings indicate that the prevalence in an urban and ageing population in the Community of Madrid is clearly higher than the Spanish average. Some authors have speculated on several possible explanations to justify this variability. It is considered that failure to identify patients who might be referenced for oxygen therapy and the lack of access to the therapy, namely the absence of financial resources, equipment and/or suppliers, could be reasons for less use of HOT in many countries. In Spain, there is great awareness of the

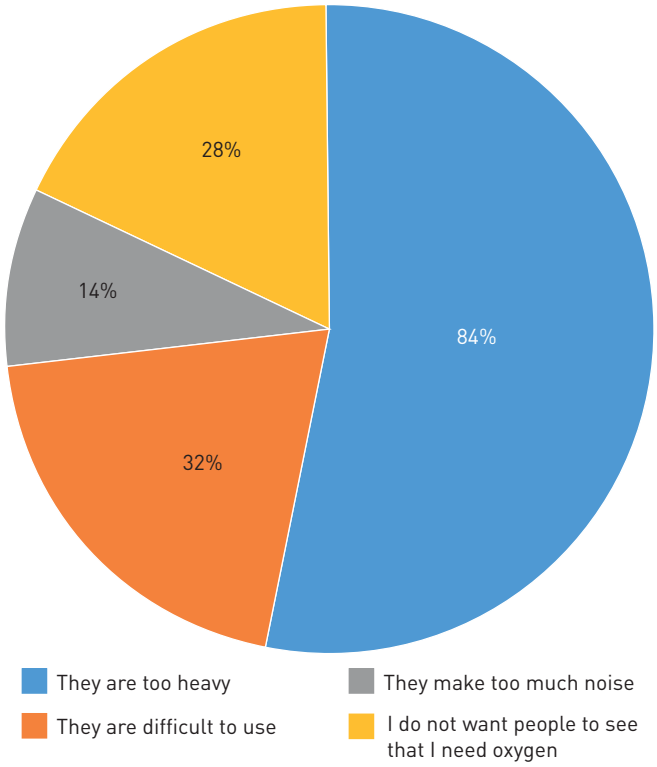


FIGURE 3 The reasons why patients did not like to use portable oxygen devices.

indications for HOT among physicians, and a wide availability of suppliers to provide the home healthcare service and the equipment needed. Table 2 shows the prescribing criteria for home oxygen therapy in Spain. Additionally, the mechanisms for reimbursement are readily available for most patients who qualify for HOT so all patients have the possibility to receive HOT, if clinically justified, with full financial coverage.

We have found a clear predominance of POC prescription in the sample analysed (99.59%) in relation to liquid oxygen. POCs were introduced to the market a few years ago and they have become the portable oxygen devices preferred by doctors and patients [7]. These are more likely to be used outside the home, as they rely on batteries and electrical power supplies, but most of the currently available POCs release the oxygen in boluses or pulses, with pulsed-dose flows that have yet to demonstrate their efficacy compared to continuous flows [12]. To address this issue, CHEN *et al.* [13] have recently compared pulse flow from a commercial POC with steady flow from a compressed oxygen cylinder. For the POC tested, pulsed doses delivered similar, though consistently lower, volume-averaged inspiratory oxygen fractions than steady flow rates equivalent to nominal pulse dose settings. Those authors hypothesised that this difference is primarily due to two factors: the increased effect of oxygen pooling for steady flow in the anatomical reservoir during slower, shallower breathing; and a delay in the arrival of the pulse, which leads to retention in the upper airways and exhalation of part of the oxygen bolus. As a rule, and according to Spanish Respiratory Society guidelines [11], the use of POCs should be restricted to patients who require low oxygen flows (<3 $L \cdot min^{-1}$) and its efficacy should always be confirmed with an standardised exercise test. However, liquid oxygen could be useful for activities that take <4 h, while POCs are the choice for activities that take longer [14]. Finally, and no less importantly, the patient should have the last word about the choice of oxygen therapy prescribed and should commit to using oxygen properly [15].

An issue related to portable oxygen prescription is that only 54.93% of the patients reported having carried out a walking test with oxygen to know the amount of oxygen they needed, 27.24% of the patients had performed the evaluation with a portable concentrator and 27.69% receiving oxygen from the wall outlet of the hospital. No walking test was performed in 45.07% of patients. Desaturation is generally defined as the presence of mean oxygen saturation measured by pulse oximetry ($S_{pO_2}$) $\leqslant$88% during a stress test such as the 6MWT, and adjustment of the oxygen flow during this test to average a $S_{pO_2}$ $\geqslant$90% is recommended. However, this is rarely done [16]. Indeed, the recommendations of some European countries suggest using the same oxygen flow indicated at rest or 1 $L \cdot min^{-1}$ more, without performing any test to assess the flow required for each patient. To check the efficacy of this therapy, the Spanish Ministry of Health and Consumer Affairs, in an order dated March 3, 1999 [17], required that the patient

TABLE 1 Overview of the results of the main questions on life habits related to portable oxygen therapy

| | |
|---|---|
| **6) When do you use this therapy?** | |
| Only during the night | 7.99% |
| Only during the day | 8.95% |
| During the day and night | 83.06% |
| **7) Why do you have a portable oxygen source (POC/portable liquid oxygen)?** | |
| Because I need oxygen all day | 31.80% |
| Because when I do an effort my blood oxygen goes down | 59.65% |
| Because when I exercise, I drown | 8.33% |
| I don't know | 0.23% |
| **10) Was a walking test with oxygen performed to know the needed oxygen amount?** | |
| No | 45.07% |
| Yes, with hospital oxygen | 27.69% |
| Yes, with a portable oxygen concentrator | 27.24% |
| **11) On average, you leave your home:** | |
| Several times a day | 8.55% |
| Once a day | 45.65% |
| Five or six times a week | 19.92% |
| Three or four times a week | 10.64% |
| One or two times a week | 7.77% |
| Two or three times a month | 3.88% |
| Less than once a month | 3.60% |
| **12) On average, how long are you out of your home?** | |
| More than 3 h a day | 17.61% |
| Between 1 and 3 h a day | 70.51% |
| Less than 1 h a day | 11.87% |
| **13) In general, how often do you use portable oxygen?** | |
| Several times a day | 6.30% |
| Once a day | 37.93% |
| Five or six times a week | 19.19% |
| Three or four times a week | 18.91% |
| One or two times a week | 8.10% |
| Two or three times a month | 4.90% |
| Less than once a month | 4.67% |
| **14) On average, how long do you use portable oxygen each time you go out?** | |
| More than 3 h | 6.25% |
| Between 2 and 3 h | 18.91% |
| Between 1 and 2 h | 46.31% |
| Between half an hour and 1 h | 19.86% |
| Less than half an hour | 8.67% |
| **15) In general, where do you use portable oxygen?** | |
| Inside your home | 1.24% |
| Outside of your home | 80.92% |
| Both outside and inside your home | 17.84% |
| **16) Outside your home, you use portable oxygen for (multiple answers):** | |
| Go for a walk | 39.45% |
| Visit family and friends | 31.63% |
| Go shopping | 17.05% |
| Go to the medical centre, clinic or hospital | 87.00% |
| **18) On average, for how long do you use portable oxygen connected to the electrical grid?** | |
| More than 3 h | |
| Between 2 and 3 h | |
| Between 1 and 2 h | |
| Between half an hour and 1 h | |
| Less than half an hour | |
| **23) How do you transport the portable oxygen?** | |
| On the shoulder | 33.54% |
| With a wheel trolley | 51.94% |
| It is carried by a family member/caregiver | 14.52% |
| **24) How do you rate the battery life?** | |
| Enough | 18.40% |
| Insufficient | 56.84% |
| Very insufficient | 24.76% |
| **25) What are the reasons you like having portable oxygen (multiple answers)?** | |
| It allows me to leave the house with less choking | 78.90% |
| It gives me the peace of mind to leave my home | 66.01% |
| At home, I can move without using extension cords | 15.91% |
| They are light and easy to use | 7.88% |
| **26) What are the reasons you do not like using portable oxygen devices (multiple answers)?** | |
| They are too heavy | 83.74% |
| They are difficult to use | 32.25% |
| They make too much noise | 13.62% |
| I do not want people to see that I need oxygen | 28.14% |

POC: portable oxygen concentrator.

TABLE 2 Prescribing criteria for home oxygen therapy in Spain

**Continuous oxygen therapy (>15 h·day$^{-1}$)**
- Indicated to improve survival and quality of life when:
  - Resting $P_{aO_2}$ ⩽55 mmHg (7.3 kPa)
  - Resting $P_{aO_2}$ between 56 and 59 mmHg (7.4–7.8 kPa) with evidence of organ damage by hypoxia (including right heart failure, pulmonary hypertension or polycythaemia)
- Not recommended in patients with COPD and moderate hypoxaemia
- Oxygen flow should be sufficient to maintain $P_{aO_2}$ >60 mmHg (8.0 kPa) or $S_{pO_2}$ >90%

**Oxygen therapy during exercise**
- May improve the quality of life of patients with exercise desaturation ($S_{pO_2}$ ⩽88%)
- Demonstration of the correction of hypoxaemia during exercise by administering oxygen ($S_{pO_2}$ ⩾90%) accompanied by an improvement of dyspnoea or exercise tolerance is required for prescription
- May be useful during exercise in patients in rehabilitation programmes, to increase the duration and intensity of training

$P_{aO_2}$: arterial oxygen tension; COPD: chronic obstructive pulmonary disease; $S_{pO_2}$: oxygen saturation measured by pulse oximetry. Reproduced and modified from [11] with permission from the publisher.

performed three 6MWTs (four if a practice walk was also performed) with and without oxygen (baseline, titrated and response evaluation) to demonstrate improved exercise tolerance. Recently, the Spanish guideline on continuous HOT [13] have stablished some recommendations for the correct adjustment of portable oxygen. According to these recommendations, we must demonstrate, in Spain, an average $S_{pO_2}$ <88% during a 6MWT and an $S_{pO_2}$ improvement (>90%) during the 6MWT on oxygen. It is necessary to perform repeated 6MWTs with different oxygen flows (even different devices) to achieve $S_{pO_2}$ ⩾90%, with a break of ⩾30 min between each test. Alternatively, we can demonstrate an increased exercise capacity in terms of a longer distance walked. In our study, no test was performed in 45.07% of our patients, which is a very important finding considering that the patients who did perform some type of walking test prior to the prescription of portable oxygen left home significantly more often than those who had not performed the test.

Although the use of POCs is restricted to patients requiring <3 L·min$^{-1}$ oxygen flow rates, our results showed that almost all patients were using POCs. Does this mean that almost all patients only required low oxygen flow, or was there inappropriate use of POCs despite the guidelines? This is a very important point to be addressed. POCs have become a very popular portable oxygen therapy in our country. Physicians prescribe POCs readily without performing any kind of test to determine their effectiveness (demonstrated by 45.07% of our patients). The database from which data was derived for our study contained no data related to oxygen titration during the exercise test. We only have data about the oxygen flow prescribed by physicians and what we have seen is that in only 317 patients, the exact prescription of oxygen flow was been expressed in litres per minute (with 59 patients needing >3 L·min$^{-1}$). In the remaining 659 patients, the registries in our database only showed the POC settings (and a position >3 was prescribed in all patients). We do not have any data on oxygen desaturation improvement. Our interpretation is that portable oxygen prescription by physicians does not concord with guidelines. In contrast, our results have shown that patients use portable oxygen properly. So, we must work on the awareness and knowledge of health professionals regarding portable oxygen therapy prescription, and promote among them the dissemination of the guidelines in order to encouraging the increase of portable oxygen titration.

Several patients complained of the excessive weight of, difficulties in handling, noise from and embarrassment of being seen with portable oxygen devices. The duration of the battery also seemed insufficient to most patients. Similarly, Arnold *et al.* [18] published an interesting study of the reasons for COPD patients not using their portable systems as prescribed and the results are very similar to those reported in this study. In their study, participants reported that they did not receive written instruction on how to use portable oxygen, were uncertain of the benefits, were afraid the system would run out of oxygen while they were using it (due to lack of confidence in the cylinder gauge), were embarrassed at being seen with the system in public and were unable to carry the system because of the cylinder weight. All these issues should be addressed to improve adherence to portable oxygen prescription and enhance the benefits related to greater mobility in these patients.

Our results show that 30% of patients use portable oxygen daily despite leaving their homes five or fewer times a week. This is a curious finding given that the Spanish regulations consider performing activities outside the home to be an essential requirement for the prescription of portable oxygen. We do not know

if there is a subgroup of patients in whom oxygen therapy provides benefits even if they do not leave home (*e.g.* those who live in large houses or houses with several floors).

The homecare provider Oximesa Nippon Gases has a training programme aiming to provide patient education on home oxygen therapy. After the prescription of oxygen to patients by the physicians, specialised nurses explain to the patients the reason they have to use oxygen; discuss all their concerns about the disease, seeking better understanding from patients and families; and explain to them what they can expect from oxygen therapy and its limits. Safety procedures are also included. Finally, trained nurses make several visits and telephone calls until the patient has understood everything. After training, patients do not have to take an examination or test to check the knowledge acquired. We can only assume that patients have carried out a training programme in portable oxygen therapy. Nonetheless, this could be one reason that would justify the good adherence found in our study, with 85% of patients leaving the home one or more times a day using oxygen.

In our study, portable oxygen was used in patients diagnosed with ILD (10%). Limited data available in the literature [19–21] suggest that many patients with ILD benefit from using oxygen: in laboratory-based tests, oxygen is associated with decreased dyspnoea or increased distance covered during a timed walk test [22, 23]. However, it has several drawbacks that threaten adherence to oxygen treatment [24]: patients are physically constrained by oxygen delivery equipment, POCs do not generate high enough flows for many patients, air travel is impossible for patients who are unable to use POCs and patients feel stigmatised when seen wearing their oxygen cannula in public [25]. Ramadurai *et al.* [26] have recently published a prospective study of 30 clinically stable ILD patients that performed two 6MWTs, one of them wearing a backpack and in the other, no backpack was worn. What the authors found in their study is that among ILD patients, carrying portable oxygen *versus* receiving oxygen *via* a stationary concentrator results in significantly greater dyspnoea and shorter distances covered in timed testing. Patients with the greatest impairment may be affected most. Considering these facts, the physician should alert patients to this effect when prescribed oxygen, and should help patients to decide on the best oxygen delivery mode to meet their personal and clinical needs.

The most important limitation of this study is that the results we reported by patients in a subjective manner and there are already studies in the literature that have shown that the patient tends to overestimate adherence compared with objective measurement monitoring in the device. The lack of information on data related to oxygen titration during the exercise test is also an important limitation.

In summary, the data obtained in our study from a large sample of patients show us that they know why they are receiving HOT and have a relatively good adherence to treatment. Portable concentrators are mainly prescribed to patients, probably due to their simplicity and greater autonomy to depend on batteries and power supply. A significant number of patients reported that they had not performed a walking test before oxygen prescription or performed any kind of oxygen titration with exercise. Our interpretation is that the portable oxygen prescriptions by physicians are not concordant with the existing guidelines. The prescription protocol and the role of the homecare provider training programme are probably two essentials factors in the results we have found. Our study has generated several hypotheses regarding long-term oxygen therapy. For example, if the patients perform a 6MWT with oxygen prior to portable oxygen therapy prescription, they are significantly more active than those who are not given a walking test. It is also an interesting finding that individuals with portable oxygen who leave home infrequently will be significantly more active at home compared to those who do not have portable oxygen. Consequently, this study may help to promote the design of future analytical studies. Additionally, more studies are needed to analyse the impact of portable oxygen therapy in COPD patients with chronic respiratory failure.

Conflict of interest: None declared.

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