Long-term oxygen therapy in chronic respiratory failure: A Multicenter Italian Study on Oxygen Therapy Adherence (MISOTA)

Margherita Neri\textsuperscript{a}, Andrea S. Melani\textsuperscript{b,*}, Anna Maria Miorelli\textsuperscript{c}, Doriana Zanchetta\textsuperscript{d}, Elisabetta Bertocco\textsuperscript{d}, Cristina Cinti\textsuperscript{e}, Piero Aldo Canessa\textsuperscript{f}, Piersante Sestini\textsuperscript{g}, on behalf of the Educational Study Group of the Italian Association of Hospital Pulmonologists (AIPO)

\textsuperscript{a}Pneumologia, Fondazione S Maugeri I.C.C.R.S Istituto Scientifico di Tradate VA, Italy
\textsuperscript{b}Fisiopatologia e Riabilitazione Respiratoria, Policlinico Le Scotte, Azienda Ospedaliera Universitaria Senese, Viale Bracci I-53100 Siena, Italy
\textsuperscript{c}Riabilitazione Respiratoria, Ospedale Armanni, Arco, Trento, Italy
\textsuperscript{d}Area Territoriale Tisio-Pneumologica, Vicenza, Italy
\textsuperscript{e}Pneumologia, Ospedale Bellaria, Bologna, Italy
\textsuperscript{f}Pneumologia, Ospedale S. Bartolomeo di Sarzana, La Spezia, Italy
\textsuperscript{g}Istituto di Malattie Apparato Respiratorio, Università di Siena, Siena, Italy

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Summary

Background: The adherence to the prescribed oxygen therapy is difficult to obtain for patients on long-term oxygen therapy (LTOT). There is little information on the modalities of oxygen utilisation for patients on LTOT who are using liquid oxygen in real life.

Study objective: Evaluation of the behaviour and the knowledge regarding LTOT in a large group of patients mainly using liquid oxygen.

Design and setting: Questionnaire administered to consecutive outpatients on domiciliary LTOT for at least 6 months referring to one of 20 clinics throughout Italy. Blinded to this result, the physician who cared for the patient completed another questionnaire.

Results: We evaluated 1504 patients (mean age 71.6 years; males 64%; 74% suffering from COPD). Most respondents (93%) used liquid oxygen with mobile device. Fifteen per cent of patients had a prescribed length of oxygen therapy less than 15 h/day; 21% reported to practice oxygen for less than 15 h/day. Patients reported using...
Introduction

Long-term oxygen therapy (LTOT) has been widely practised in Italy as well as in other western countries for many years, on the grounds of its proven demonstrations of efficacy acknowledged by the scientific community.\(^1\)\(^,\)\(^2\) Recently its value has been confirmed in the joint statement of leading international Scientific Societies of Respiratory Medicine.\(^3\) LTOT is effective on survival if the supplements of oxygen useful to maintain the arterial oxygen tension (\(P_{\text{aO}_2}\)) above 8 kPa are administered for at least 15 h/day.\(^1\)\(^,\)\(^2\) LTOT is very compelling for patients. Since its first demonstration of efficacy, the adherence to the prescribed oxygen therapy resulted a problem for patients on LTOT.\(^1\) The largest information on the adherence to LTOT comes from countries,\(^4\)\(^-\)\(^7\) where most patients were using gaseous oxygen and concentrators. As many patients on domiciliary LTOT go outside the house, the use of liquid oxygen, ideally suited for the easy filling of portable systems at home, could possibly improve compliance to the prescribed treatment.\(^8\)\(^,\)\(^9\) Effectively, some studies have shown that selected patients use liquid oxygen longer than gaseous oxygen.\(^9\)\(^,\)\(^10\) However, due to its extensive cost, the generalised diffusion of liquid oxygen remains uncommon, although increasing, in most western countries.

The peculiarity of the Italian situation is that almost everywhere exclusively liquid oxygen is used, while gaseous oxygen is reserved only for the terminally ill or in temporary situations as dyspnea relief in acute bronchitis reexacerbations. Concentrators are rarely used, mainly because the regulations until very recently made such a prescription very complicated under the National Health Service.

The primary aim of this survey was the evaluation of the behaviour and the knowledge about oxygen therapy in a large group of patients on LTOT, mainly using liquid oxygen. Other aims were to evaluate how well the information supplied by prescribing physicians as regards times and modality of oxygen use corresponds to what patients say they have been told. How well LTOT prescriptions correspond to international criteria. How well founded the impressions of many pulmonologists are on the need to give patients on LTOT more ample and detailed explanations in order to improve their understanding and compliance to treatment.

Material and methods

This survey was an open, multicentre, observational study promoted by the Italian Association of Hospital Pulmonologists (AIPO) Educational Group. Twenty chest clinics throughout Italy (listed below) took part in the study, carried out between April 2002 and March 2003. A questionnaire was consecutively administered to all outpatients, reporting to one of the clinics, who had been on domiciliary LTOT for at least 6 months. The participating centres were distributed throughout the whole national territory and included both urban and rural areas; hence they can be considered as representative of the Italian national context. In order to standardise the design of the survey, periodic meetings were held with and phone contacts made to all participants before and during the study period. The questionnaire (see
reproduction) was printed, computer-scannable and preliminarily prepared by the A IPO Educational Group members. The questionnaire consisted of 26 and 33 closed-type questions, written on the back and front of a single sheet of paper, to be completed, respectively, by the physician and patient. The responses of the patient were blinded to the physician and vice versa. Its comprehensi-
bility and reliability had also been tested during a preliminary phase by a group of patients that were not enrolled in the present study. Informed consent was obtained from the patients at the moment of collecting the data (Appendix).

Unless stated otherwise, results are presented as absolute numbers, or in percentage, or as mean ± sd. Univariate statistical analysis of categorical variables was performed using **2 test, and logistic regression was used when appropriate to adjust for relevant confounders. Analysis of continuous variables was performed using Student’s t test or ANOVA as appropriate. Comparison between patient- and doctor-reported use of oxygen was performed using the non-parametric rank sum test, while the agreement between the two sources was evaluated using Cohen’s k coefficient. All P values were calculated by two-tailed distribution, and values equal or lower than 0.05 for a two-tailed distribution were considered statistically significant. All the analyses were performed using the statistical package Stata 8 on a PC-compatible personal computer (Stata corp, College Station, TX).

Results

We collected 1504 questionnaires (mean number of questionnaires per centre, 75). No patient on LTOT who satisfied the inclusion criteria did refuse to participate in the study. Ninety-hundred and nine (60%) questionnaires were filled in by males, 596 (40%) by females; mean (±sd) age of partici-
pants was 71.6 (±10 sd) years. One thousand three hundred and forty-one patients (93% of respondents) used liquid oxygen, 82 (6%) a concentrator and 21 (1%) gaseous oxygen. Patients characteristics are shown in Table 1. Ninety per cent of patients were already registered at the Centre in which they were recruited; 10% were first time patients at the recruiting centre; this subset had therefore received their LTOT prescription elsewhere. The physician who first prescribed LTOT was a respiratory specia-
list in 94% of cases. The first prescription of LTOT was made less than 1 year preceding the survey in 18% of cases, between 1 and 2 years in 21%, between 2 and 5 years in 38%, more than 5 years in 23%. The educational level of patients who responded to the question (data missing in 9% of questionnaires) was: no formal education in 8.7%, primary education in 60.2%, lower middle school in 17.3%, secondary education in 10.5%, and university education in 3.3%. All patients (except nine subjects) were retired. Concerning the smoking habits (Table 1), 6.5% of patients responded that they still smoked despite the disease and oxygen therapy. The highest percentage of current smokers was in the COPD group.

As Table 2 shows, 206 patients on LTOT also used a ventilator, of which 17% a volumetric device, 58% Bi-level, 18% CPAP, 7% not specified. Patients declared that they used the ventilator everyday in 99% of cases: 11% said they used the ventilator for less than 5 h/day, 56% for 6–9 h/day, 33% for more than 9 h.

### Table 1  Some characteristics of enrolled patients.

<table>
<thead>
<tr>
<th>Respiratory diagnosis</th>
<th>Number (%)</th>
<th>Mean (± sd)</th>
<th>% Male</th>
<th>Smoking status (current smokers/never smokers/former smokers, %)</th>
<th>FEV₁ (± sd) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD</td>
<td>1041 (74)</td>
<td>72 ± 9</td>
<td>66</td>
<td>8/23/69</td>
<td>46 ± 16</td>
</tr>
<tr>
<td>Interstitial lung disease</td>
<td>169 (12)</td>
<td>70 ± 10</td>
<td>57</td>
<td>1/50/49</td>
<td>55 ± 18</td>
</tr>
<tr>
<td>Fibrosis post-TB</td>
<td>142 (10)</td>
<td>73 ± 8</td>
<td>54</td>
<td>3/48/49</td>
<td>41 ± 14</td>
</tr>
<tr>
<td>Bronchiectasis</td>
<td>89 (6)</td>
<td>70 ± 11</td>
<td>62</td>
<td>1/44/55</td>
<td>43 ± 13</td>
</tr>
<tr>
<td>Cancer</td>
<td>50 (4)</td>
<td>71 ± 10</td>
<td>82</td>
<td>6/17/77</td>
<td>62 ± 13</td>
</tr>
<tr>
<td>Kyphoscoliosis</td>
<td>43 (4)</td>
<td>66 ± 11</td>
<td>30</td>
<td>2/80/18</td>
<td>50 ± 18</td>
</tr>
<tr>
<td>Obesity</td>
<td>62 (5)</td>
<td>63 ± 16</td>
<td>29</td>
<td>0/75/25</td>
<td>55 ± 15</td>
</tr>
<tr>
<td>Obstructive sleep apnoea</td>
<td>44 (4)</td>
<td>62 ± 13</td>
<td>45</td>
<td>5/70/25</td>
<td>55 ± 16</td>
</tr>
<tr>
<td>Neuromuscular disease</td>
<td>8 (0.1)</td>
<td>46 ± 29</td>
<td>63</td>
<td>0/88/12</td>
<td>54 ± 8</td>
</tr>
</tbody>
</table>

*The total number of patients according to the respiratory diagnosis is greater than the total number of enrolled patients because it was possible for the doctor to fill in more than 1 answer (for example, COPD and bronchiectasis).
Concerning the prescribed length of oxygen therapy reported by the physician (Tables 3 and 4), the indication was to practice less than 15 h/day in a significant percentage of cases, independently of the respiratory diagnosis. The indication to modify the oxygen flow in the different situations of everyday life was reported by the physician in 45% of cases. A detailed list of the oxygen flows prescribed by the physician in the various situations of everyday life is reported in Table 5. The most common indication was to increase the oxygen flow during exercise (84% of total). At the last follow-up visit, 24.9% of 1309 patients showed the $\text{PaO}_2$ greater than 8 kPa at rest whilst breathing air and 40.4% of 1288 patients had the oxyhemoglobin saturation greater than 89%. The original prescribed flow of oxygen had in the course of time been modified in 52% of patients. The prescription had been modified on the basis of the arterial blood gases analysis (BGA) in 94% of cases; in 56% only the BGA had been carried out; in 38% BGA and pulse oxymetry had been performed. In eight cases (out of a total of 745 responses) the prescription had been modified solely on the basis of the clinical examination.

Twenty-one per cent of patients reported to practice oxygen therapy for less than 15 h/day. Evaluating the variables related to the group of patients that claimed to practice a daily length of oxygen therapy <15 h, when they had a greater length of oxygen prescription by the physician, we did not find any impact of age, gender, duration of LTOT introduction, respiratory diagnosis and degree of instruction. On the contrary, the $\text{PaO}_2$ greater than 8 kPa at the last follow-up visit was associated to less compliance (12% vs. 16%; $P = 0.05$), as well as a greater flow of oxygen at rest ($\chi^2$ test for trend $P < 0.001$). Patients reported using oxygen for less hours than had been prescribed by the physician both at rest during the day ($P = 0.02$, $k = 0.80$) and the night ($P = 0.0036$, $k = 0.77$), as well as during exercise ($P = 0.002$, $k = 0.72$). Particularly, we found a good relationship between the flow of oxygen prescribed at rest during the day by the physician and that known and reported by the patient (NS, sign rank and 0.83 at the Cohen test), as well as the flow prescribed in the night during sleep by the physician and that known and reported

Table 2 Number of patients on LTOT who also used a ventilator according to their diagnosis.

<table>
<thead>
<tr>
<th>Main diagnosis</th>
<th>No*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kyphoscoliosis</td>
<td>26</td>
</tr>
<tr>
<td>Bronchiectasis</td>
<td>6</td>
</tr>
<tr>
<td>Obesity</td>
<td>44</td>
</tr>
<tr>
<td>Obstructive sleep apnoea</td>
<td>32</td>
</tr>
<tr>
<td>Neuromuscular disease</td>
<td>7</td>
</tr>
<tr>
<td>COPD</td>
<td>127</td>
</tr>
<tr>
<td>Interstitial lung disease</td>
<td>5</td>
</tr>
<tr>
<td>Fibrosis post-TB</td>
<td>23</td>
</tr>
<tr>
<td>Not specified</td>
<td>3</td>
</tr>
</tbody>
</table>

*The total number of patients according to the respiratory diagnosis is greater than the total number of ventilated patients because it was possible for the doctor to fill in more than 1 answer.

Table 3 Prescribed daily length of oxygen therapy reported by the physician at the last follow-up visit.

<table>
<thead>
<tr>
<th>Hours/day</th>
<th>No of patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 9</td>
<td>38 (3%)</td>
</tr>
<tr>
<td>9–14</td>
<td>172 (12%)</td>
</tr>
<tr>
<td>15–20</td>
<td>683 (50%)</td>
</tr>
<tr>
<td>21–24</td>
<td>496 (35%)</td>
</tr>
</tbody>
</table>

Table 4 Some details of LTOT prescription reported by the physician according to the respiratory diagnosis.

<table>
<thead>
<tr>
<th>Respiratory diagnosis</th>
<th>Prescription &lt;15 h/day, number of patients (%)</th>
<th>Indication to vary oxygen flow in the various situations of everyday life (% of responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD</td>
<td>109 (11)</td>
<td>41</td>
</tr>
<tr>
<td>Interstitial lung disease</td>
<td>18 (11)</td>
<td>56</td>
</tr>
<tr>
<td>Fibrosis post-TB</td>
<td>14 (11)</td>
<td>54</td>
</tr>
<tr>
<td>Bronchiectasis</td>
<td>7 (9)</td>
<td>69</td>
</tr>
<tr>
<td>Cancer</td>
<td>12 (25)</td>
<td>32</td>
</tr>
<tr>
<td>Kyphoscoliosis</td>
<td>6 (8)</td>
<td>53</td>
</tr>
<tr>
<td>Obesity</td>
<td>15 (22)</td>
<td>24</td>
</tr>
<tr>
<td>Obstructive sleep apnoea</td>
<td>13 (31)</td>
<td>13</td>
</tr>
<tr>
<td>Neuromuscular disease</td>
<td>1 (12)</td>
<td>12</td>
</tr>
</tbody>
</table>
by the patient (NS, with \( k = 0.82 \)). On the contrary, we found a marked discrepancy between the flow prescribed by the physician during exercise and that known and reported by the patient \( (P < 0.00003 \text{ with } k = 0.78) \). Patients reported using the flow that they knew had been prescribed by the physician both at rest during the day (NS; \( P = 0.1 \)) and during exercise (NS; \( P = 0.1 \)), but at a lower level \( (P = 0.008) \) in the night. Of the 1232 patients (84%) possessing a rechargeable portable device, only 992 responded to the questions on its use: 47% reported recharging it daily, 17% twice weekly, 10% seldom, 26% only when they go outside for many hours. However, only 41% reported using the stroller always when outside the house. As Table 6 shows, a large number of patients either did not respond to this question or said that they were ashamed of being seen by passers-by with the portable device.

Ninety-six per cent of patients had made scheduled periodical control in the referring centre; of these, 24% reported monthly visits, 65% at intervals from 2 to 4 months. However, 66% of patients had made at least one unscheduled visit for respiratory problems and 9% had made up to five in the course of the last year.

As Table 7 shows, only 2% of patients claimed they had not received any information on the correct use of oxygen. The great majority of those who had received information (79% of cases) said they had received it from a respiratory specialist.

<table>
<thead>
<tr>
<th>Oxygen prescription (L/min)</th>
<th>Percentage of responses at rest</th>
<th>Percentage of responses in the night</th>
<th>Percentage of responses during exercise</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1</td>
<td>5.3</td>
<td>6.1</td>
<td>1.9</td>
</tr>
<tr>
<td>1</td>
<td>27.3</td>
<td>31.5</td>
<td>15.6</td>
</tr>
<tr>
<td>1.5</td>
<td>29.3</td>
<td>28.7</td>
<td>18.7</td>
</tr>
<tr>
<td>2</td>
<td>25.9</td>
<td>22.0</td>
<td>29.9</td>
</tr>
<tr>
<td>2.5</td>
<td>4.5</td>
<td>3.9</td>
<td>9.9</td>
</tr>
<tr>
<td>3</td>
<td>4.3</td>
<td>4.3</td>
<td>12.9</td>
</tr>
<tr>
<td>&gt;3</td>
<td>3.4</td>
<td>3.5</td>
<td>11.1</td>
</tr>
</tbody>
</table>

Table 6  Main reasons causing the use of the stroller less than prescribed.

<table>
<thead>
<tr>
<th>Heavy Not use</th>
<th>I forget</th>
<th>Uncomfortable</th>
<th>Shame</th>
</tr>
</thead>
<tbody>
<tr>
<td>26%</td>
<td>11%</td>
<td>6%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Table 7  Source of information on the correct use of oxygen.

<table>
<thead>
<tr>
<th>Figure</th>
<th>Percentage of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pulmonologist</td>
<td>79</td>
</tr>
<tr>
<td>Nurse</td>
<td>27</td>
</tr>
<tr>
<td>Respiratory therapist</td>
<td>8</td>
</tr>
<tr>
<td>General practitioner</td>
<td>7</td>
</tr>
<tr>
<td>Commercial technician who delivers oxygen</td>
<td>34</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>2</td>
</tr>
<tr>
<td>Others</td>
<td>2</td>
</tr>
<tr>
<td>Nobody</td>
<td>2</td>
</tr>
</tbody>
</table>

The total percentage is more than 100% because more than 1 answer was allowed.

Table 8  Did you perceive an improvement after starting oxygen use?

<table>
<thead>
<tr>
<th>No</th>
<th>Immediately</th>
<th>After some days</th>
<th>After weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>12%</td>
<td>52%</td>
<td>19%</td>
<td>16%</td>
</tr>
</tbody>
</table>

Only 12% of patients reported that they did not perceive a subjective improvement with oxygen use; most patients reported that they perceived a subjective improvement immediately after commencing use (Table 8). Those who did not notice any improvement after oxygen use tended to use oxygen less time than prescribed \( (65 \pm 20\text{min. less than prescribed}) \), but the difference was not significant \( (P < 0.065) \) compared to those who found an improvement (and who did 29 \( \pm 6 \text{min} \) less than prescribed). The perception of an improvement probably constituted a stimulus to correct use. On
patients’ response to the question concerning their knowledge about the rationale for oxygen therapy, the correct response was the most frequent one: “they gave me oxygen because I have little in the blood” (51%); nevertheless it remains of concern that 48.5% did not give this answer; of these, 38.5% said instead generically that “it was on account of dyspnea”.

Discussion

In Italy there are approximately 50,000 patients on domiciliary LTOT, but, except for a few regions, precise numerical data are lacking. The National Health Service fully covers expenses of LTOT. LTOT prescription, in terms of the norms governing its use (e.g. professional competence for prescription required, modalities), is quite homogeneous in all regions of Italy. A pulmonary specialist of the National Health Service usually effectuates LTOT prescription; anaesthetists or paediatricians seldom prescribe LTOT, but only in exceptional cases can other specialists do so. Our study confirms this view: respiratory specialists catered for 94% of LTOT prescriptions. Another peculiarity, confirmed by our survey, is the widespread use of liquid oxygen, even for elderly patients.

The questions on LTOT prescribed by the physician highlight some problems. We observed that a significant proportion of patients received the LTOT prescription for respiratory failure not derived from COPD. However, even if the benefits of LTOT in terms of survival have been documented only for COPD patients, it is common practice to use LTOT for chronic respiratory failure from any cause. A significant number of our patients (15%) received the prescription for oxygen use of less than 15 h/day. Another consistent group (25%) had the basal $P_aO_2$ higher than 8 kPa at the last follow-up visit. These data are cause of concern because they do not correspond to evidence-based recommendations for good clinical practice. Moreover, various studies have documented similar situations. In France and in Denmark, respectively, 18% and 11% of patients on LTOT had the $PaO_2$ greater than 8 kPa at rest whilst breathing air. The greater percentage in our survey may be due to the slightly different inclusion criteria for LTOT prescription between these countries. In another study carried out in the UK, 46% of patients with LTOT had values greater than 90% with pulse oximetry. In France and in the Netherlands, respectively, 24% and 35% of COPD patients on LTOT had a prescription for oxygen use less than 15 h/day. To keep patients well oxygenated, patients frequently need extra oxygen during sleep and exercise. Some chest physicians recommend an increase of resting oxygen flow by 1 l/min for sleep and exercise, whereas others individualise flow rates with or without specific testing of each patient. As liquid oxygen is suitable to assure good mobility and most patients in our survey were using liquid oxygen, we were not surprising that most physicians increased the oxygen flow on exercise. On the contrary, when during the sleep a variation of the oxygen flow was suggested, we often observed a reduction rather than an increase.

On the part of patients we found a fair, though not optimal, compliance to the physician’s prescription. We, as others, found an association between good compliance to the prescribed oxygen therapy and severity of resting hypoxemia. However, in our study the compliance to oxygen therapy was based on self-reported data. It is known that patients tend to overestimate their oxygen usage. In a Danish study, 13% of patients reported to use oxygen less than 15 h/day, but an objective evaluation showed that the effective percentage was approximately of 35% of the total. To our knowledge, no survey has evaluated how patients follow medical prescriptions on oxygen flow in different situations. We found that the indications supplied by the physician on oxygen use concord reasonably well with what the patient remembers except for physical exercise. Likewise, patients knew what the physician had prescribed, but in a significant proportion of cases did not comply with this in reality. This was true mainly for the oxygen flow in the night.

Portable oxygen therapy has been shown to relieve breathlessness and increase exercise tolerance in selected patients. Our data confirm that portable liquid oxygen is useful in hypoxaemic patients to decrease breathlessness. A significant number of our patients reported to use oxygen for treating breathlessness. Kampelmacher et al. reported a similar percentage of patients claiming that LTOT had been prescribed for reducing breathlessness. Likewise, to the question whether they were using a mobile system supplying oxygen outdoors, a large number of our patients either did not respond or reported that they did not use it, often because they were ashamed of being seen by passers-by with the stroller. Other authors, mainly using gas cylinders as mobile source, reported shame as a common cause, which limited the use of oxygen outdoors. In a very different reality with most patients using gaseous oxygen or concentrators, but, on the other hand, similarly to us, a low
use of mobile sources of oxygen when going outside the house has been reported, particularly if they had not received specific instructions in regard. In another multicentre study including 159 COPD patients, only 60% of patients in the group with portable sources used their mobile system outdoors without any difference between gaseous and liquid oxygen. Thus our survey confirms the use of liquid oxygen does not automatically assure a good adherence to the prescribed treatment or the use of supplemental oxygen outdoors. Probably whatever the type of used oxygen source there is need to provide repeated educational sessions to patients on LTOT to extend hours of oxygen therapy outside the house and obtain a good compliance. In fact, although our patients felt that they had received in-depth and exhaustive information concerning oxygen therapy, their behaviour did not always reflect what they have learnt.

We conclude that in Italy most patients on LTOT used liquid oxygen. Patients felt they had improved as a result of LTOT and were satisfied with the degree of information concerning oxygen therapy. Adherence to prescription was acceptable with a tendency to undertreatment in terms of length of daily oxygen therapy and, intentionally, of flow rate when breathing oxygen during sleep and, non-intentionally, on exercise. The use of liquid oxygen did not automatically increase the adherence to the prescribed treatment and the hours of oxygen therapy outside the house. On the physicians’ side, we found that the appropriateness of the prescriptions was good, but the criteria utilised did not always correspond to evidence-based recommendations.

Good LTOT practice requires a lot of work both by means of self-assessment on the part of physicians of their own mode of operating (periodic audits under the guidance of an expert pulmonologist?) and through a program of in-depth education of the patient, patient’s relatives and also of the general population, which must learn to accept as natural the presence of people using portable devices.

List of all the participating Centres of the AIPO Educational Study Group:

(1) Margherita Neri, Pneumologia, Fondazione S Maugeri I.C.C.R.S Istituto Scientifico di Tradate VA.
(2) Andrea S. Melani, Roberta Bruscoli, Fisiopatologia e Riabilitazione Respiratoria, Policlinico Le Scotte, Azienda Ospedaliera Universitaria Senese, Siena, Piersante Sestini, Clinica Malattie Apparato Respiratorio, Università di Siena, Siena.
(3) Anna Maria Miorelli, Riabilitazione Respiratoria, Ospedale Armani, Arco, Trento.
(4) Dorianzanchetta, Elisabetta Bertocco, Area Territoriale Tisio-Pneumologica, Vicenza.
(5) Cristina Cinti, Vincenzo Mariano, Pneumotisiatria Azienda USL Città di Bologna, Bologna.
(6) Natalino Barbato, Pneumologia, Ospedale da Procida, Salerno.
(7) Maria Aliani, Pneumologia, Fondazione Maugeri IRCCS, Cassano Murge, Bari.
(8) Marco Bonavia, Pneumologia, Ospedale La Colletta, Arenzano, Genova.
(9) Vita Cappiello, Pneumologia, Potenza.
(10) Vincenzo Cilenti, Fisiopatologia Respiratoria, Istituto Regina Elena, Roma.
(12) Giuditta Donati, Antonio Dezio, Tisio-Pneumologia, Ospedale di Marzana, Verona.
(13) Giuseppe De Angelis, Broncopneumologia e Riabilitazione Respiratoria, Ospedale Forlanini, Roma.
(14) Giacomo Grande, Clinica delle Magnolie, Caserta, Italy.
(15) Paola Martucci, Angelo Sena, Broncopneumologia, Ospedale Cardarelli, Napoli.
(16) Vittore Martini, Azienda Sanitaria Locale Senese, Medicina, Ospedale di Nottola, Montepulciano (Siena), Italy.
(17) Guido Basetti Sanì, Azienda Sanitaria Locale Firenze, Fisiopatologia Respiratoria, Ospedale I.O.T. Firenze, Italy.
(19) Piero Aldo Canessa, Pneumologia, Ospedale S.Bartolomeo di Sarzana, La Spezia.
(20) Stefano Aiolfi, Riabilitazione Respiratoria, Ospedale S.Marta, Rivolta d’Adda, CR.

Appendix

Multicenter Italian Study on Oxygen Therapy Adherence

To be completed by the physician

Patient general information
1. Sex: Male Female
2. Age: Tens Units

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To be completed by the physician

Patient general information
1. Sex: Male Female
2. Age: Tens Units

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To be completed by the physician

Patient general information
1. Sex: Male Female
2. Age: Tens Units

---

To be completed by the physician

Patient general information
1. Sex: Male Female
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To be completed by the physician

Patient general information
1. Sex: Male Female
2. Age: Tens Units

---

To be completed by the physician

Patient general information
1. Sex: Male Female
2. Age: Tens Units

---

To be completed by the physician

Patient general information
1. Sex: Male Female
2. Age: Tens Units
3. Marital status:  Married  Never married
Widowed  Separated/divorced

4. Educational level:  None  Upper middle school
Elementary school  University
Lower middle school

5. Patient:  Has made previous visits to the Centre taking part in the study
First-time visitor

Patient’s disease
6. The patient’s disease is: (more than one answer possible)
   - Chronic respiratory failure  COPD
   - Diffuse interstitial lung disease  TB sequelae
   - Bronchiectasis  Kyphoscoliosis/other thoracic cage deformities
   - Neuromuscular diseases  Apnea
   - Severe obesity  Bronchopulmonary neoplasia
   - Other ........................................

Ventilatory therapy
7. Is ventilatory support prescribed in association?
8. If a ventilator is used what type is it?
   - Volumetric
   - CPAP
   - Intermittent positive airway pressure
9. How many hours a day is the ventilator used?
   - Not every day ..................................

Diagnosis and prescription
10. Date of first diagnosis of respiratory failure
    - Less than one year ago  more than 5 years ago
    - From 1 to less than 2 years ago  precise date unknown
    - From 2 to less than 5 years ago
11. Date of first prescription of oxygen therapy
    - Less than 1 year ago  more than 5 years ago
    - From 1 to less than 2 years ago  precise date unknown
    - From 2 to less than 5 years ago
12. Who first prescribed the oxygen therapy?
    - Local family doctor  Intensive care specialist
    - Pneumologist  Other specialist
13. The latest prescription indicates how many hours of oxygen therapy per day

Oxygen flow
14. Is the oxygen flow unvaried throughout the whole day?
    - Yes  No
15. If no, in which circumstances is the flow to be varied?
    - At night  During exercise
16. What is the prescribed O$_2$ flow at rest in liters?
17. What is the prescribed O$_2$ flow at night in liters?
18. What is the prescribed O$_2$ flow during exercise in liters?
19. The prescription of oxygen therapy is through what form?
    - Liquid oxygen  Concentrator  Gas canister
20. If liquid oxygen was prescribed was a portable device also supplied?  Yes  No
21. Oxygen is delivered through:
    - mask  Canula
    - nasal prongs  By tracheostomy level
    - esthetic eyeglasses
Variations
22. With respect to the original prescription have any changes in oxygen flow or time been prescribed?
   Yes    No
23. If yes, these changes were made on the basis of: (more than one answer possible)
   Clinical examination    Blood gases analysis
   Pulse oximetry (oxyhemoglobin saturation)
24. FEV₁ % pred.
   Tens
   Units
25. Last $\text{PaO}_2$ evaluated in room air at rest in stable conditions in mmHg:
26. Last $\text{SpO}_2$ evaluated in room air at rest in stable conditions in %:

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To be completed by the patient

1. When were you first prescribed oxygen therapy?
   Less than 1 year ago    more than 5 years ago
   From 1 to 2 years ago   I don’t remember
   From 2 to 5 years ago
2. How many liters of oxygen were you prescribed?
   At rest
   At night
   During exercise
3. What is the total number of hours, on average, per day that you use oxygen?
   Less than 8 
4. How many liters of oxygen do you usually use?
   At rest
   At night
   During exercise
5. Who explained to you in detail how to use oxygen? (more than one answer possible)
   Firm representative    Physiotherapist    Pharmacist
   Family doctor          Nurses            Nobody
   Medical specialist     Other
6. Why were you prescribed oxygen? (more than one answer possible)
   I don’t know
   I have chronic bronchitis
   I have emphysema
   I have little oxygen in the blood
   I am short of breath
   Other
7. How often on average do you change your nasal prongs (or mask, or canula)?
   Every 2–3 months
   At least once a month
   After more than 3 months
   When they break
8. And the replacement part is usually:
   Supplied by my ASL
   Bought at my own expense
   Supplied by the firm
   Got from the hospital when I go for a check-up
9. Do you use a gurgler to humidify your oxygen?
   Yes    No
10. If yes, do you use
    Water from the tap
    Distilled or demineralised water?
11. The water for your humidifier:
    I top it up as the level goes down
    Periodically I change the whole tank
12. Do you have periodic visits and/or examinations to check up on your oxygen therapy?
   Yes  No

13. If yes, how often on average do you have such check-ups?
   Once a month  Once every 5–8 months
   Once every 2 months  Once a year or longer
   Once every 3–4 months

14. If yes, what check-up examinations do you do? (more than one answer possible)
   Visit to the doctor  Breath test
   Arterial blood test to measure oxygen
   Assessment of oxygen saturation without blood test

NB: because of a print error, there is no question 15

16. Do you have a portable oxygen device?  Yes  No
17. If yes, do you use it regularly?  Yes  No

18. How often do you fill up your portable device?
   Every day
   Twice a week
   Once in a while, only when I am out of the house for many hours
   Rarely

19. When you go out of the house do you use your portable device?
   Always  Sometimes
   Hardly ever or never

20. If you use your portable oxygen device, how many hours (filling it up to the top) does the flow, normally prescribed for you, last?
   Less than 2 h  From 2 to 5 h  More than 5 h

21. If you do not use your portable oxygen device, or use it less than you are supposed to, this is because:
   It is too heavy  I have little need of it  I forget it
   It complicates things  It bothers me to be seen by others

22. Do you know the name of the firm that supplies the oxygen?  No  Yes (specify) . . . . . .

23. Since you began using oxygen:
   I have not noticed any improvement in my health
   I immediately noticed an improvement in my health
   I had an improvement, but only after a few days
   I had an improvement, but only after a few weeks

24. Since you have been using oxygen:
   I can do physical exercise or move better than before
   I have not noticed any difference
   Things are worse than before

25. To which of the following categories do you belong?
   Never smoked  Ex-smoker
   Used to smoke and still do occasionally  Current smoker

26. If you are an ex-smoker, approximately how many years ago did you quit smoking?
   Less than 1 year ago  From 1 to 5 years ago  More than 5 years ago

27. If you smoke or used to smoke, how many cigarettes per day on average do or did you smoke?
   Less than 10  From 10 to 20  More than a packet

28. If you smoke or used to smoke, for how many years approximately?
   Less than 10  From 10 to 25  From 25 to 40  More than 40
29. If you smoke or used to smoke, did someone advise you/prescribe to quit smoking? (more than one answer possible)

<table>
<thead>
<tr>
<th>Firm representative</th>
<th>Physiotherapist</th>
<th>Pharmacist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family doctor</td>
<td>Nurses</td>
<td>Nobody</td>
</tr>
<tr>
<td>Medical specialist</td>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

30. Do you consider you received sufficiently detailed information on the correct use of oxygen therapy?

<table>
<thead>
<tr>
<th>Yes, but I could have received more</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

31. How many unscheduled visits for respiratory problems have you made to a doctor in the last 365 days?

<table>
<thead>
<tr>
<th>None</th>
<th>1</th>
<th>2–3</th>
<th>4–5</th>
<th>More than 5</th>
</tr>
</thead>
</table>

32. How many times has your catarrh increased in volume or worsened in appearance in the last 365 days?

<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2–3</th>
<th>4–5</th>
<th>More than 5</th>
</tr>
</thead>
</table>

33. How many times have you used an antibiotic for respiratory problems?

<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2–3</th>
<th>4–5</th>
<th>More than 5</th>
</tr>
</thead>
</table>

34. How many medicines, including aerosols, sprays, tablets, plasters and/or injections, have you taken per day on average over the last 365 days?

<table>
<thead>
<tr>
<th>None</th>
<th>1–3</th>
<th>4–5</th>
<th>5–9</th>
<th>More than 10</th>
</tr>
</thead>
</table>

References


