Characteristics and complaints of patients prescribed long-term oxygen therapy in the Netherlands


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In patients prescribed long-term oxygen therapy (LTOT), compliance is often poor. Both patient- and treatment-related factors seem to be involved. As a base for improvements in LTOT, the characteristics and complaints of LTOT patients were investigated.

A survey was set up in a random sample of clients of the largest oxygen company in the Netherlands. Patients were selected if they were ≥18 years old, had a phone and if they had had oxygen equipment for ≥6 months. All patients were visited at home by a medical student. Data are presented for a total of 528 patients (response rate 62%). The typical LTOT patient was a 70-year-old male with chronic obstructive pulmonary disease (COPD), who had had oxygen equipment for 3-5 years and who used oxygen cylinders and nasal cannulae for 13 h day⁻¹. Twenty percent of the patients still smoked. Although LTOT was prescribed in 80% of the patients by a chest physician, prescription was often inadequate. Only 33% of the patients were informed adequately about the therapy. Twenty percent of the patients used oxygen for fewer hours per day than prescribed. Non-compliant patients were mainly men (P=0.006) and more often ashamed of their therapy (P=0.023) than compliant patients. The blood oxygen level was monitored regularly in 73% of the patients. Most complaints concerned the oxygen equipment, especially the concentrator. The single most important complaint had to do with restricted autonomy. Only 19% of the patients had no complaints at all.

It is concluded that LTOT should be improved with regard to the education, motivation and monitoring of patients. The prescribing physician needs to be included in an education programme. Given the numerous problems these patients experience, LTOT should be improved in particular with regard to equipment convenience.

Introduction

In patients with chronic obstructive pulmonary disease (COPD) and chronic hypoxaemia, long-term oxygen therapy (LTOT) improved survival and reduced clinical deterioration over a 3-year period (1,2). An effect was only demonstrated if oxygen was used for at least 15 h day⁻¹, with greater benefit for longer periods. International guidelines, therefore, recommend the prescription of 15 h day⁻¹ as a minimum (3,4). However, if LTOT is prescribed according to these guidelines, it imposes a considerable burden on many patients. Consequently, compliance to treatment is poor (5–7). Compliance may, amongst other factors, be affected by patient characteristics, such as motivation and severity of disease symptoms, information about the disease and the therapy, and, especially, by the perceived discomfort of the treatment itself (5–8). Attempts to improve compliance should, therefore, be based on knowledge of the characteristics and the complaints of these patients.

In 1991, data on the characteristics and complaints of LTOT patients in the Netherlands were lacking. At the same time, relevant epidemiological data in the literature often originated from (chest) physicians instead of patients, contained only a small number of patients, and differed from country to country (9–12). Moreover, studies looking into the complaints of LTOT patients were scarce. This all led to the aim of the present study, namely to investigate the characteristics and complaints in patients who had been
prescribed LTOT in the Netherlands. These data might allow for comparisons with data of LTOT patients in other countries, and could possibly serve as a base for improvements in LTOT.

**Methods**

To avoid biased patient selection, a survey was set up in a sample of 4500 clients of the largest oxygen company in the Netherlands (Hoek Loos). For reasons of travelling distances, the file was restricted to 2523 patients. After they had been coded by number, 1381 of them were randomized by computer. The selection criteria were: (a) being ≥ 18 years old; (b) having a phone; and (c) having oxygen equipment for ≥ 6 months. Eligible patients received an explanatory letter together with a reply card from the oxygen company. The name and phone number of a patient were only handed to the investigators if the card stated a positive reply. The patient was then phoned to arrange a home visit by a medical student. All patients were visited between 1 October, 1991 and 1 April, 1992.

Prior to the visit, 15 students had been trained in formulating the 145 questions of a structured questionnaire, which referred to demographic data, the prescribing physician, the illness, smoking habits and mobility. Prescription, usage, equipment, follow-up and coping with treatment were examined in detail. Students were instructed that all questions had to be answered by the patients themselves.

To estimate the representativeness of the patient sample, the oxygen company was requested to complete two additional questionnaires. One for the patients who had been interviewed and given informed consent, and one for the patients who had refused the interview. The former questionnaire only referred to the amounts of daily oxygen prescribed and used, whereas the latter also referred to age, diagnosis, sex, duration of LTOT, smoking habits and oxygen source. For reasons of privacy, the latter set of questions had to be answered anonymously. Finally, 1 year after the last interview, the number of eligible patients who had died was extracted from the file of the oxygen company. The study was approved by the Medical Ethics Committee of the University Hospital Utrecht.

**STATISTICAL ANALYSIS**

Data analysis and descriptive statistics were performed using the SPSS/PC+ program (SPSS Inc., Chigaco, U.S.A.). Subgroups were compared using t-tests and Mann–Whitney U-tests for continuous variables, and by χ² tests in contingency tables for categorical variables. Continuous values are reported as mean ± standard deviation; all P values relate to two-tailed comparisons and were considered statistically significant if <0.05.

**Results**

Of the 895 patients selected, 341 (38%) refused to participate. Twenty-six of the remaining 554 patients could not be interviewed for reasons of severe illness or early death. Therefore, data are presented for 371 men (70%) and 157 women, with a median age of 70 years (range 19-89-91-9), who had been on LTOT for a mean of 3.5 ± 3.6 (0.5-33) years. The patients’ diagnoses for which LTOT had been prescribed are listed in Table 1. There were 350 ex-smokers. Of the 108 smokers, 75 (69%) had a lung disease and 15 smoked while using oxygen. Eighty-nine patients (17%) were housebound and 117 (22%) lived alone. In 389 patients (70%), the costs of LTOT were reimbursed by the Dutch National Health Service; the remaining patients were privately insured.

In 421 patients (80%), LTOT was prescribed by a chest physician; in 58 (11%), by a general practitioner; and in 49
TABLE 2. Frequency of patients' complaints about their oxygen source

<table>
<thead>
<tr>
<th>Oxygen source</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxygen cylinders (n=421)</td>
<td>34%</td>
</tr>
<tr>
<td>Transport of the cylinders</td>
<td>20%</td>
</tr>
<tr>
<td>Changing the pressure valve</td>
<td>18%</td>
</tr>
<tr>
<td>Size and appearance of the cylinders</td>
<td>5%</td>
</tr>
<tr>
<td>Frequent deliveries</td>
<td>3%</td>
</tr>
<tr>
<td>Oxygen concentrator (n=76)</td>
<td>55%</td>
</tr>
<tr>
<td>Vibrations and/or noise (46 dBA)</td>
<td>45%</td>
</tr>
<tr>
<td>Technical problems</td>
<td>41%</td>
</tr>
<tr>
<td>Power failure(s)</td>
<td>23%</td>
</tr>
<tr>
<td>Transportation problems</td>
<td>10%</td>
</tr>
<tr>
<td>Condensation in the oxygen hose</td>
<td>7%</td>
</tr>
<tr>
<td>Fragility of the machine</td>
<td>1%</td>
</tr>
<tr>
<td>Liquid oxygen (n=20)</td>
<td>35%</td>
</tr>
<tr>
<td>Chance of frostbite</td>
<td>20%</td>
</tr>
<tr>
<td>Dependency on the stationary canister</td>
<td>10%</td>
</tr>
<tr>
<td>Need for sufficient ventilation</td>
<td>5%</td>
</tr>
</tbody>
</table>

(9%), by a non-chest physician (internist, cardiologist, neurologist or E.N.T. specialist) (Table 1). Dyspnoea and hypoxaemia were the most important reasons for starting LTOT, in 243 (46%) and 196 patients (37%), respectively. Dyspnoea reduced after LTOT had begun in 34% of 479 patients. Only 175 patients (33%) stated that they had been given instructions for the use of oxygen, generally by the oxygen company.

The oxygen prescription and usage were unknown to 202 and 32 patients, respectively. In the remaining patients, oxygen was prescribed for $15.8 \pm 7.4$ h day$^{-1}$ and used for $12.7 \pm 8.0$ h day$^{-1}$. The mean of the individual differences between the amounts of daily oxygen prescribed and used was $-0.6 \pm 3.2$ h day$^{-1}$ (n=324). Sixty-four patients (20%) used oxygen for less hours per day than prescribed because of the difficulties they experienced with the treatment, absence of dyspnoea or fear of becoming addicted to oxygen. Compared to the compliant patients, the non-compliant patients were more frequently males (P=0.006) and more often ashamed of their therapy (P=0.023). Compliant and non-compliant patients did not differ significantly with respect to age, diagnosis, duration of LTOT, oxygen source, smoking cessation, and number and type of complaints (other than shame).

A total of 430 patients (81%) used oxygen cylinders (10 l, 20 kg); 71 (13%) used a MC 44 oxygen concentrator (DeVilbiss Healthcare, U.S.A.); 19 (4%) used liquid oxygen; and eight (2%) used a combination of these. Patients using a concentrator complained more often about their equipment than patients using either cylinders or liquid oxygen (P<0.001) (Table 2). Of the 316 patients (63%) who had received portable cylinders, 86 (27%) did not use them at all, 54 (16%) used them sporadically and only 19 (18%) carried the cylinders themselves.

Nasal cannulae were used by 435 patients (82%), a nasal catheter by 49 (9%), a face mask by 16 (3%), a cuffed nasal catheter by 15 (3%), a combination of these by seven (1%), and a transtracheal microcatheter by six patients.
were prescribed LTOT by a non-chest physician. Although prescribe oxygen. As a result, 15% of the COPD patients mean oxygen prescription was in agreement with international guidelines, the standard deviation was large, indicating that many patients were treated inadequately. In reason to initiate LTOT. The fact that this therapy is not few studies available, patients were rarely directly asked for typical negative experiences.

As has been demonstrated by others, patients who use a concentrator are troubled most (13–15). Comparison with other studies is, however, difficult as studies that have looked into the complaints of LTOT patients are scarce. Moreover, in the few studies available, patients were rarely directly asked for negative experiences.

In addition, this study shows that in the Netherlands, the typical LTOT patient is a 70-year-old male COPD patient who has had oxygen equipment for 3.5 years and who has been using oxygen cylinders and nasal cannulae for a mean of 13 h day$^{-1}$. Although this is, in many respects, in agreement with findings from other countries, there are some differences which make it difficult to transfer the present results to those of other countries (9–12,16–18). For example, in Scotland and Sweden, the mean age of patients was somewhat lower (9,18). This may be due to an earlier start of LTOT in these countries due to the implementation of clear guidelines. In France and Sweden, oxygen was prescribed in 18–24% of the LTOT patients because of hypoxaemia due to sequelae of tuberculosis. In the Netherlands, this is rarely an indication for LTOT (9,19).

In France, Poland, Sweden and Switzerland, most patients have oxygen concentrators, whereas in Italy, most patients use liquid oxygen (20,21). These differences may be explained by the local density and accessibility of patients, and by the reimbursement policies of each country.

In the Netherlands, almost any physician is allowed to prescribe oxygen. As a result, 15% of the COPD patients were prescribed LTOT by a non-chest physician. Although mean oxygen prescription was in agreement with international guidelines, the standard deviation was large, indicating that many patients were treated inadequately. In 46% of the patients, dyspnoea was the most important reason to initiate LTOT. The fact that this therapy is not for symptomatic relief of dyspnoea and that this complaint is not always caused by hypoxaemia may explain why LTOT caused a reduction of dyspnoea in only 34% of the patients (22–24). Only 33% of the patients were informed about side-effects and the way oxygen had to be used. However, it is the duty of the prescribing physician to educate and motivate the patient in this respect (25,26).

Twenty percent of the patients used oxygen for less hours than prescribed, mostly because of shame and absence of dyspnoea. Compliance was not related to the number or type of complaints, except for shame. Patients especially experienced difficulties when using oxygen during the day; only 31% used oxygen while walking indoors, 29% while eating, 21% while taking a bath or shower, and only 20% when going out. The latter may be attributed to shame and impaired mobility. The weight of the portable cylinder (5.5 kg) caused many patients to leave their oxygen at home when going out. For LTOT patients who are still ambulant, liquid oxygen might be a better alternative. In fact, the number of patients using liquid oxygen who went out while still connected to the equipment was higher than that of patients with portable cylinders ($P=0.002$), which is in accordance with the literature (7,27). Most patients were monitored regularly, but encouragement to increase the daily oxygen use was only given to a minority of them. It is important, though, that patients with an accepted indication for LTOT are urged to use oxygen for at least 15 h day$^{-1}$ (1–3). To assess oxygenation, blood gas analysis was used instead of pulse oximetry in 87% of the patients. Although pulse oximetry should not be used as a substitute for arterial oxygen tension measurements for LTOT prescription, it is an excellent means for checking LTOT patients (28,29).

Despite the high incidence of significant disability observed, organized home care was lacking. The only structural support for the patients was through the oxygen company. A home care programme, with a nurse making home visits, may provide a better solution than regular visits to an outpatient department (7,15,21).

There are some limitations to the present investigation. First, due to its random nature, several data may differ from objective data, especially with regard to prescription, usage and compliance. Patients usually tend to overestimate their oxygen usage, thus improving their compliance (7). Second, in order to exclude patients who used oxygen for palliative reasons, only patients having oxygen equipment for at least 6 months were selected. Next, data from the oxygen company were often missing or not up to date. Due to privacy regulations, data on the diagnosis, sex or smoking habits of the non-respondents were not available.

Finally, the response rate of eligible patients was moderate. Since this reflects both the willingness and the ability to participate in the study, patients may have refused an interview because of the severity of their illness. The 1-year mortality rate was in fact significantly higher in the non-respondents than in the respondents, even though the former were prescribed oxygen for less hours per day than the latter. This may be caused by the fact that the non-respondents were prescribed LTOT at a later stage in their disease or by inadequate prescription (13,30). Age may

![Fig 3. Number of categories of complaints due to long-term oxygen therapy (LTOT) (n=528).](image-url)
Table 3. Comparison of some of the characteristics of the 528 respondents and 341 non-respondents

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Respondents (n=528)</th>
<th>Non-respondents (n=341)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>68.4 ± 11.1</td>
<td>70.2 ± 11.0</td>
<td>0.03</td>
</tr>
<tr>
<td>Duration of LTOT (years)</td>
<td>3.2 ± 3.6</td>
<td>2.4 ± 2.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>1-year mortality rate [no. (%)]</td>
<td>134 (25)</td>
<td>141 (42)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Prescription (1 day⁻¹)</td>
<td>173 ± 1768</td>
<td>816 ± 808</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Consumption (1 day⁻¹)</td>
<td>994 ± 1346</td>
<td>592 ± 699</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Compliance (1 day⁻¹)</td>
<td>-228 ± 1728</td>
<td>-210 ± 684</td>
<td>NS</td>
</tr>
<tr>
<td>Oxygen source [no. (%)]</td>
<td>528 (100)</td>
<td>205 (100)</td>
<td>0.03</td>
</tr>
<tr>
<td>Cylinders [no. (%)]</td>
<td>430 (81)</td>
<td>183 (89)</td>
<td></td>
</tr>
<tr>
<td>Concentrator [no. (%)]</td>
<td>78 (15)</td>
<td>16 (8)</td>
<td></td>
</tr>
<tr>
<td>Liquid oxygen [no. (%)]</td>
<td>20 (4)</td>
<td>6 (3)</td>
<td></td>
</tr>
</tbody>
</table>

NS, not significant; LTOT, long-term oxygen therapy.

have played a role as well, since 52% of the respondents compared to 62% of the non-respondents were over the age of 70 years (P<0.01). In addition, the poor 1-year survival in the non-respondents may have been caused by a greater number of smokers and a different distribution of diseases (13,30). Despite the abovementioned factors, the patient sample of this study seems adequate as it represented almost 10% of the LTOT patients in the Netherlands.

It is concluded that LTOT might be improved with regard to the education, motivation and monitoring of patients. The prescribing physician needs to be included in an education programme. Given the numerous problems these patients experience, LTOT should be improved, particularly with regard to equipment convenience.

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