Home oxygen therapy program for infants after neonatal unit discharge: report of a ten-year experience

Programa de oxigenoterapia domiciliar para crianças egressas de uma unidade neonatal: relato da experiência de dez anos

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ABSTRACT

Objective: To describe the results of a home oxygen therapy program consisting of the use of oxygen concentrator by children discharged from a neonatal unit during their first 10 years of the program.

Methods: Cross-sectional analytical study with data collection from November 1996 to December 2006. All infants that needed home oxygen therapy after discharge from the neonatal unit of a university hospital in the state of São Paulo, Brazil, were studied.

Results: We identified 160 infants who used home oxygen therapy during the period and 63.3% of them had bronchopulmonary dysplasia. A mean of 3.0% of all hospitalized patients and 8.6% of very low birth weight newborns were discharged on oxygen. The mean duration of home oxygen therapy was 42.3±54.0 days. Significant differences were not found when comparing demographic characteristics of the population and duration of home oxygen therapy. There was no correlation between the duration of mechanical ventilation and the duration of home oxygen therapy. In addition to the use of oxygen and medications, 22.3% of the infants needed special care. In the first 2 years of life, the infants’ morbidity and mortality rates were, respectively, 40.1% and 14.1%.

Conclusions: The use of an oxygen concentrator at home is a feasible therapeutic alternative in Brazil; therefore, it deserves more attention from health professionals and greater investments from health institutions. Further national studies are needed to improve the quality of care and the safety of these programs intended for the neonatal population.

Key-words: oxygen therapy; bronchopulmonary dysplasia; premature infant; neonatology; home nursing.
duração da terapia domiciliar. Houve necessidade de cuidados especiais, além do uso de O₂ e medicações, em 22,3% dos casos. Nos primeiros dois anos de vida, a taxa de morbidade e de mortalidade foram, respectivamente, 40,1 e 14,1%.

Conclusões: O uso de oxigênio domiciliar, com sistema de concentrador de oxigênio, é uma alternativa terapêutica factível em nosso meio, merecendo mais atenção dos profissionais de saúde e maior investimento das instituições de saúde. São necessários mais estudos nacionais para se aprimorar a qualidade do atendimento e a segurança destes programas para a população neonatal.

Palavras-chave: oxigenoterapia; displasia broncopulmonar; prematuro; neonatologia; assistência domiciliar.

Introduction

Home oxygen therapy has been used for about 50 years. However, the fact that this therapy promotes the quality of life and increases the life expectancy of adults with chronic obstructive pulmonary disease was only confirmed in the 1970s(1).

As a consequence of the technological advances in the treatment of very premature newborns (NBs), bronchopulmonary dysplasia (BPD) became a cause of prolonged hospital stay because of the chronic oxygen dependency(2,3). The increased length of hospital stay is accompanied by risk of hospital infections, family separation, and high costs for the health institutions(3,4). In this context, the implementation of home oxygen therapy programs has important medical, economic, and social implications.

Home oxygen therapy programs for children with BPD have been used for nearly 40 years(5). Oxygen supply through nasal cannulas keeps adequate levels of oxygen partial pressure, reducing both pulmonary vascular resistance(6) and upper airway resistance(7), in addition to decreasing the risk of sudden death(8) and promoting weight gain(9,10).

In Latin America, few studies have been published on home oxygen therapy in neonates. In Chile, this type of treatment started to be used in 1990 and, since 2003, this country has a national program of home oxygen therapy(11). In Brazil, we could not find reports on this topic in newborns, and there are few studies involving children(3). According to the Brazilian Neonatal Research Network, from January 2006 to June 2008, only 3% of the NBs with birth weight between 500 and 1500g who were born in eight hospitals in the South and Southeast regions of the country used home oxygen therapy(12).

The use of home oxygen therapy, when appropriately recommended, does not increase the risk of rehospitalizations or causes higher costs, even considering the expenses with outpatient follow-up(12). Taking into consideration the hospital resources that can be saved(4,12), the optimization of the use of beds, and the difficulties related to the access to and financing of neonatal health care in Brazil, it is relevant to describe a 10-year experience of a home oxygen therapy program using oxygen concentrators offered to children discharged from a neonatal unit and to analyze the tendency of this therapy throughout this period.

Methods

We conducted an analytical, observational, cross-sectional study to describe the prevalence of use and the characteristics of the population receiving home oxygen therapy by means of oxygen concentrators used by children discharged from the neonatal unit of a public university hospital located in the state of São Paulo, Brazil, from November 1996 to December 2006. We also analyzed the tendency of this type of therapy during ten years.

The study included all cases identified in the period whose medical records were available and who were discharged on home oxygen therapy. The inclusion criterion of the home oxygen therapy program was continuous clinical need of oxygen detected after several attempts to discontinue the therapy in NBs with appropriate clinical and social conditions for discharge.

Throughout the study period, we followed the guidelines recommended by the American Academy of Pediatrics - AAP (1998) for discharge(13): clinical stability, need of low oxygen concentrations with maximum acceptable flow rate of 1 L/min through nasal cannula to keep SaO₂ using pulse oximetry between 90-94%(14). For patients with heart diseases, the appropriate levels of SaO₂ were individually evaluated. The hospital also adopted the following criteria for discharge: absence of apnea for at least 48 hours, rising weight curve, and weight higher than 2000g at discharge, as well as appropriate household and family conditions.

After the family agreed with discharge on oxygen therapy, the social work team examined the requirements necessary for the proper functioning of the program for each case: availability of physical space, power supply, financial resources for payment of the lighting bill, distance between home and primary health care unit, and availability of transportation for the routine and emergency visits.
Simultaneously, the primary health care unit was informed to make transportation easier for the families. Next, the hospital rented oxygen tanks and oxygen concentrators. These devices were lent to the families. These patients did not use pulse oximeters at home.

The oxygen concentrator (Air Liquide®) is a device powered by electricity and equipped with a molecular filter to extract nitrogen and other gases from room air and enriched it with oxygen up to concentrations between 90-95% depending on the flow rate ranging from 0.25 to 5 L/min. This equipment also enables the patient to move while using it because it features wheels, has lower risk of explosion, and does not need to be refilled\(^{(1,15)}\).

Before hospital discharge, the mothers were trained to use the system (concentrator/tank) since mothers and patients stayed in hospital together. While in hospital, the mothers were provided with information on how to handle the oxygen tank and concentrator, on how to change the oxygen flow rate from 0.25 to 5 L/min in case of cyanosis/increase of respiratory effort, and about the measures to be taken in emergency situations. The mothers were also given the telephone numbers of the technical assistance for this equipment. They also received information on general care, diet, and medications.

After discharge, the patients returned for outpatient visits once a week to assess the possibility of intermittent or total discontinuation of the oxygen therapy and overall follow-up. During these follow-up visits, the oxygen therapy was discontinued and the children were monitored by means of pulse oximetry for several hours, with the SaO\(_2\) being observed during sleep\(^{(16)}\), while the patients ate\(^{(17)}\), and when they were awake\(^{(16)}\). The thresholds of pulse oximetry used during the follow-up visits were the same ones used during hospital stay\(^{(18)}\). After oxygen therapy discontinuation, the NBs were followed up until they were two years old.

The demographic variables evaluated were: birth weight, gender, gestational age according to Capurro\(^{(18)}\) or New Ballard method\(^{(19)}\), underlying disease associated with oxygen dependency, duration of oxygen therapy during hospital stay, length of hospital stay, postmenstrual weight and age (gestational age plus the postnatal period of life in weeks) at hospital discharge, duration of parent training, number of outpatient visits and rehospitalizations, causes of death, corrected age at home oxygen therapy discontinuation and duration of home oxygen therapy in days, socioeconomic conditions, and educational level of the family members. We also evaluated diet, medications, devices or procedures (tubes, tracheostomies, gastrostomies, upper airway suction) used by NBs at hospital discharge and complications caused by the use of the concentrator (fire, equipment problems or damage leading to discontinuation of the oxygen therapy).

Statistical analysis was performed using the SAS System for Windows (Statistical Analysis System), version 9.1.3 Service Pack 3, SAS Institute Inc, 2002-2003, Cary, NC, USA. We performed a descriptive analysis with calculation of means, medians, standard deviations, and minimum and maximum values. The trend of frequencies of oxygen use per year was checked using the Cochran-Armitage test. We used Spearman’s correlation coefficient to investigate the linear association between duration of oxygen therapy during hospital stay and at home for patients with BPD. ANOVA rank transformation was used to compare continuous values throughout the years. The significance level for statistical tests was 0.05. This study was approved by the Research Ethics Committee of the hospital.

Results

We identified 160 NBs who were discharged from hospital on home oxygen therapy. Because of difficult access to the medical records, we could not get information about two cases. Of all cases, 128 (81%) were preterm infants and 80 (50.6%) were males. The description of the population studied, length of hospital stay, and duration of oxygen use while in hospital and at home, as well as corrected age at hospital discharge and at oxygen therapy discontinuation are shown in Table 1. The duration of oxygen therapy at home was established for 131 patients.

The main diseases associated with chronic oxygen dependency are shown in Table 2. The mean±SD of birth weight and gestational age of NBs with BPD were, respectively, 1047.5±414.4 g and 29.7±2.8 weeks. During hospitalization, oxygen was administered using tents, hoods, and nasal cannulas. In addition to oxygen inhalation, 127 cases (83%) used invasive mechanical ventilation. Mean±SD for this variable was 20.2±19.6 days, ranging from 1 to 86 days. Regarding the use of continuous positive airway pressure (CPAP), 88 cases (58%) used this method with a mean duration of 5.5±5.3 days. In NBs with BDP, there was no significant correlation between the total time of oxygen therapy or between the duration of mechanical ventilation during hospital stay and the duration of oxygen therapy at home.

We found that ten NBs (7.6%) used oxygen at home for less than one week, and three cases used oxygen therapy for
Table 1 - Birth weight and weight at discharge, gestational age and postmenstrual age at discharge, total duration of use of oxygen during hospital stay, length of hospital stay, and total duration of home oxygen therapy (n=158)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Median</th>
<th>SD</th>
<th>Min-max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth weight (g)</td>
<td>1554.0</td>
<td>1675.0</td>
<td>898.4</td>
<td>510-4040</td>
</tr>
<tr>
<td>Gestational age (weeks)</td>
<td>32.0</td>
<td>31.9</td>
<td>4.3</td>
<td>25-42</td>
</tr>
<tr>
<td>O₂ during hospital stay (d)</td>
<td>73.3</td>
<td>70.0</td>
<td>39.1</td>
<td>10-260</td>
</tr>
<tr>
<td>Length of hospital stay (d)</td>
<td>74.2</td>
<td>69.0</td>
<td>39.7</td>
<td>12-257</td>
</tr>
<tr>
<td>Weight at discharge (g)</td>
<td>2633.0</td>
<td>2450.0</td>
<td>579.4</td>
<td>1890-4620</td>
</tr>
<tr>
<td>PMA at discharge (weeks)</td>
<td>42.5</td>
<td>41.3</td>
<td>5.2</td>
<td>35-64</td>
</tr>
<tr>
<td>Home O₂ (d)*</td>
<td>42.3</td>
<td>22</td>
<td>54.0</td>
<td>2-347</td>
</tr>
</tbody>
</table>

PMA = postmenstrual age, SD = standard deviation, Min = minimum value, Max = maximum value, g = grams, d = days, *Data for 131 cases

Table 2 - Absolute and relative distribution of the diagnoses associated with indication of home O₂ (n=155)

<table>
<thead>
<tr>
<th>Diseases*</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bronchopulmonary dysplasia</td>
<td>100</td>
<td>64.5</td>
</tr>
<tr>
<td>Gastroesophageal reflux disease</td>
<td>49</td>
<td>32.0</td>
</tr>
<tr>
<td>Hear diseases</td>
<td>12</td>
<td>7.7</td>
</tr>
<tr>
<td>Sequelae of hypoxic-ischemic syndrome</td>
<td>12</td>
<td>7.7</td>
</tr>
<tr>
<td>Chest wall restriction</td>
<td>7</td>
<td>4.5</td>
</tr>
<tr>
<td>Genetic syndromes</td>
<td>7</td>
<td>4.5</td>
</tr>
<tr>
<td>Thoracic-lumbar myelomeningocele</td>
<td>5</td>
<td>3.2</td>
</tr>
<tr>
<td>Sequelae of pneumonia</td>
<td>3</td>
<td>1.5</td>
</tr>
<tr>
<td>Pulmonary hypoplasia</td>
<td>2</td>
<td>1.3</td>
</tr>
</tbody>
</table>

*Data not available for 3 cases; *39 cases with more than one diagnosis

only three days. Ten cases remained more than 150 days on home oxygen therapy. Three of these cases had heart diseases, four had BPD associated with gastroesophageal reflux disease (GERD), and three had only BPD.

There were not significant differences over the years (Figure 1) regarding the distribution of the number of cases that used home oxygen therapy per year compared with the total number of inpatients and with all NBs with birth weight below 1500g. The mean frequency of home oxygen therapy for the total number of NBs hospitalized and for NBs weighing <1500g was, respectively, 3.0 and 8.6%.

There were not significant differences when comparing the years regarding birth weight, gestational age, length of hospital stay, corrected age at hospital discharge and at oxygen therapy discontinuation. The duration of use of home oxygen did not vary significantly during the ten years of the program (Figure 2).
In relation to the care provided to patients at home, the mean ± SD of the number of doses of medications administered by caregivers was 4.6±3.5, ranging from one to 16 daily doses. Thirty-one NBs (22.3%) were discharged from hospital using enteral tubes, six (4.3%) were using gastrostomy tubes, and three (2.2%) were using tracheostomy tubes. The period of training and guidance to the mothers regarding discharge showed mean ± SD of 1.3±0.7 days (ranging from one to six days).

We could only investigate the socioeconomic and educational level of a small subsample of the population (n=20) from 2003 to 2006. The per capita income of the families was of R$ 189.0±88.0 (mean±SD), ranging from R$ 80.0 to R$ 387.5. In terms of education, 5% and 45% of mothers only completed elementary school and high school, respectively. Forty percent and 10% of the cases had incomplete elementary and high school, respectively.

There were no records of possible complications related to the use of oxygen concentrators at home.

Data were recorded on the outpatient follow-up of 127 NBs on home oxygen therapy, of whom 114 were followed up during the first two years of life. Fifty-one cases (40.1%) had at least one rehospitalization caused by lung disease. We found that 18 patients (14.1%) died during this period, and eight of them (6.2%) were still using oxygen at home when they experienced worsening of disease and were rehospitalized. They died of respiratory failure.

Discussion

The home oxygen therapy program, which was implemented in the hospital in 1996, was used on average by 3.0% of inpatients and 8.6% of NBs weighing less than 1500g at birth. Bronchopulmonary dysplasia was the most prevalent disease among these NBs.

We expected that the experience gained during these ten years, combined with the technical and scientific advances, would lead to three changes in the demographic profile of this population, namely: reduced gestational age, birth weight, and corrected age at discharge. However, both the demographic characteristics and the frequency of oxygen use did not vary during the study. This may be associated with the maintenance of the discharge criteria in this period, especially in relation to the parameters of SaO2 used by the hospital: weight at discharge higher than 2000g and social status of the families. In addition, the high level of dependency and severity of the patients, which may have prevented earlier hospital discharge, contributed to these findings.

In studies on home oxygen therapy conducted during the last decade, the population investigated had mean gestational age ranging from 25.2 to 28.5 weeks20,21 and birth weight from 737 to 1106g20,22, both lower than the values we found in the present study. However, the corrected age at discharge was higher or lower than the ones found in our study21,23, which may reflect differences in terms of discharge protocols. Another aspect that may explain these differences is the inclusion in the present study of all NBs who needed oxygen therapy and not only those with bronchopulmonary dysplasia.

With regard to the duration of home oxygen therapy, the mean use in other hospitals ranged from 63 to 97 days8,21 and, in our study, it was 42.3±54.0 days. We assume that this result is related to: differences in the SaO2 thresholds used in the different centers24, inclusion in the present sample of patients with heart diseases and neurological disorders with higher gestational age, and differences in the socioeconomic level among the populations. In certain situations, depending on income and living conditions, it was necessary to prolong the hospital stay to guarantee a safe discharge, which may have contributed to the shorter duration of oxygen therapy at home.

In the present study, BPD was the most common disease, which is in agreement with the literature8,21,23, followed by GERD. We believe that the high incidence of GERD among these patients is also associated with the frequent diagnostic tests for this disease in our service during the period investigated25.

The frequency of use of home oxygen therapy by very low birth weight NBs varies widely among different centers. It is possible to find values as low as 1% and as high as 37% of use26,27. In our study, this frequency varied over time; however, it did not show statistical significance. Oscillations in the frequency of use of home oxygen therapy in the same hospital have also been found by other authors25. Many differences, both intra- and inter-hospitals, may contribute to these findings. Among them, one may consider the size of the hospital and the size of the population of very low birth weight NBs, the medical team’s concern about the impact and costs of this therapy for the family16,24,26, the lack of definition about the values of SaO2 recommended for these patients16,20,24,26,28, and the uncertainties regarding the benefits of oxygen therapy29,30. Despite these uncer-
tainties, the value of \(\text{SaO}_2 < 90\%\) is the most often used for supplemental oxygen\(^{16,24,26}\).

Another important aspect of the present study is the lack of correlation between duration of mechanical ventilation and use of oxygen during hospital stay and duration of home oxygen therapy. We suspected that there was a significant positive correlation between these two variables, indicating higher severity of the underlying disease. However, there are multiple indications for mechanical ventilation in preterm infants, including sepsis and apnea of prematurity. Thus, a long period of mechanical ventilation or use of intra-hospital oxygen may not correlate with prolonged oxygen dependency.

Infants with BPD and prolonged use of oxygen also had other limitations that delayed discharge, such as poor sucking, use of enteral tubes, tracheostomies, and administration of a large number of drugs. Therefore, it is essential to have a specialized nursing team to train the caregivers. This team must be able to effectively evaluate and follow up the patients after discharge\(^{41}\). With that purpose, the mothers were educated about basic hygiene care, placement of tubes and catheters, and proper administration of medications ranging from one to 16 daily doses. This measure was also aimed at alleviating the fears of caregivers, since there may be consequences to the mental health of the mothers\(^{20,22}\).

The literature shows common pulmonary morbidities in the first two years of life of patients on home oxygen therapy with high rates of rehospitalizations, ranging from 45 to 83\%\(^{2,32}\). In the present study, 40\% of the children were rehospitalized at least once after discharge. We could not get recent and specific information on mortality after discharge in preterm infants using oxygen at home. Data from at least a decade ago showed that the mortality rate after discharge for preterm infants with BPD may range from 8 to 20\%\(^{33}\).

Because of the shortage of financial resources and support from the health system for the home care of patients using oxygen, the program could only offer care after discharge in the hospital, unlike other reports\(^{23,32}\). In addition, heart monitors or pulse oximeters were not used at home. There is no evidence that such monitoring could improve the results of home oxygen therapy. However, some hospitals use these devices to adjust the oxygen flow rate\(^{54}\) and identify the displacement of the catheter\(^{32}\). Nevertheless, false alarms produced by these devices may be a source of stress for caregivers\(^{34}\). A limitation of the present study is the fact that it is a retrospective study, which may have caused underreporting of information. Thus, it was not possible to accurately assess the complications taking place at home. Moreover, the socioeconomic status was only identified for a small sample of the population. However, the results presented here suggest that, even with a low socioeconomic level, it is possible to provide home oxygen therapy as an alternative to prolonged hospitalization. Because of these limitations, it is necessary to plan a specific study to further clarify the socioeconomic conditions and possible unmet needs during the follow-up period of families, since there may be a negative impact on the quality of life of these families\(^{20,22}\).

By analyzing the results over ten years, the present study demonstrated that the use of home oxygen therapy is a feasible therapeutic alternative in Brazil and it deserves more attention from health professionals and greater investment from health institutions. In this context, further studies are needed to provide better quality and safety to this type of treatment.

References

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