Management of infants on home oxygen

Improvements in survival of premature babies over the last two decades are mainly attributed to the use of antenatal steroids and postnatal surfactant therapy. Despite this reduction in mortality, there has not been an overall reduction in chronic lung disease of prematurity. This article discusses the evidence available and the authors' experience of managing infants on home oxygen from a tertiary neonatal unit.

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Key points

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- 1. The management of chronic lung disease remains one of the challenges of neonatal care.
- Home oxygen can provide major benefits in terms of growth, development and parent-infant bonding whilst reducing overall care cost.
- 3. There is a lack of evidence to guide practice in the management of infants on home oxygen.
- 4. Recent changes in the prescription and supply of home oxygen are described.

Anagement of babies with chronic lung disease (CLD) remains one of the challenges of neonatal care. Around twenty percent of infants with a birth weight less than 1500g will be affected with CLD¹. A proportion of these infants will ultimately be discharged from the neonatal unit on home oxygen therapy. Once babies are clinically stable, major benefits can be obtained from discharge to the home environment. There is a lack of evidence to provide guidelines in this area and consequently a wide variety of practice exists throughout the UK².

Chronic lung disease

Definitions of chronic lung disease vary from oxygen dependency at 28 days after birth to 36 weeks' postmenstrual age with or without other criteria such as chest radiograph changes. Bronchopulmonary dysplasia is a pathological diagnosis referring to lung findings at post mortem however this term now often appears to be used interchangeably with CLD. This article will consider babies who require supplemental oxygen at discharge from the neonatal unit due to respiratory complications of prematurity (other diagnoses such as congenital heart disease and neuromuscular conditions are not covered). These babies are clinically stable with a persisting oxygen requirement but do not require ongoing hospital care.

The use of long term oxygen therapy in chronic lung disease

It has been suggested that oxygen therapy improves a number of outcomes in CLD both in terms of morbidity and mortality. Hypoxia impairs normal cellular function, which may cause tissue damage. Chronic hypoxia contributes to the development of pulmonary hypertension and right heart failure. It may also predispose to acute life

- Reduction in pulmonary hypertension
- Reduction in intermittent desaturations and apnoeas
- Improvement in growth
- An aid to parent-child bonding
- Normal environment for development
- Reduction in care cost

TABLE 1. Potential benefits of home oxygentherapy.

threatening events (ALTE).

Hyperoxia can also be harmful to the neonate. It is an aetiological factor for retinopathy of prematurity and it has also been implicated in the aetiology of bronchopulmonary dysplasia and periventricular leucomalacia. Oxygen toxicity may actually inhibit lung healing and perpetuate the process of lung injury³. Although excessive oxygen is potentially damaging, concerns about hyperoxia should not result in suboptimal treatment with supplemental oxygen.

It has been suggested that the incidence of sudden unexpected death in infants with CLD has been reduced through the use of long-term supplemental oxygen⁴. Arterial oxygen saturations less than 90% have been shown to be associated with an increased risk of sudden unexpected infant death and ALTE5. High variability in arterial oxygen saturation has also been shown to predict sudden unexpected infant death and ALTE with high specificity and sensitivity. Forty-six percent of preterm infants readmitted with ALTE have been shown to have previously unrecognised hypoxaemic episodes or low baseline arterial oxygen saturations⁶.

Oxygen therapy improves respiratory control, reducing apnoeas and episodic desaturations and also decreases the amount of time spent in periodic breathing⁴.

HOME OXYGEN

The pulmonary vascular bed in infants with CLD and pulmonary hypertension is responsive to supplemental oxygen and this has been shown to reduce pulmonary hypertension⁷.

There are many other benefits of oxygen therapy in CLD, summarised in **TABLE 1**. Improvements in growth have been shown with the use of home oxygen. In cohort studies supplemental oxygen has been shown to allow infants with CLD to grow as well as healthy term infants⁸. The optimal saturation limits for adequate growth however are unclear. The recent BOOST Trial showed no significant improvement in longer term growth when higher saturation targets (95-98% vs. 91-94%, on Nellcor monitors) were used⁹.

The precise relationship between the level of oxygen supplementation and neurodevelopmental outcome remains to be determined. Requirement for oxygen at discharge from hospital has not been shown to predict developmental score. Follow-up studies of very low birthweight infants have shown, perhaps unexpectedly, that those who required less oxygen and ventilation had more severe cerebral palsy10. Interpretation of these results could suggest that aggressively managing hypoxia may improve outcomes. It is thought that minimising hypoxaemia is likely to improve neurodevelopmental outcomes¹⁰. However this is yet to be demonstrated in clinical trials; the BOOST and STOP-ROP trials have not shown any difference in neurodevelopmental outcome when a higher saturation range is targeted^{9,11}.

What saturation targets should be used?

To provide safe effective oxygen therapy we must control both hypoxia and hyperoxia.

The arterial partial pressure of oxygen (PaO_2) is the gold standard measurement of systemic oxygenation. The acceptable range of PaO_2 in neonates has been suggested to be 6-10 kPa (45-75mmHg) although the evidence to support this is not from randomised trials¹². Arterial blood sampling however is not an appropriate measure in stable neonates who will anyway become hypoxic when crying.

Pulse oximeters allow continuous or intermittent non-invasive measurement of arterial oxygenation and are generally accepted as the measuring device of choice in CLD.

Pulse oximeter saturation (SpO₂) is accurate to within 2% of arterial saturation

 (SaO_2) . There is a non-linear relationship between SaO_2 and PaO_2 and therefore SpO_2 cannot be used directly to calculate PaO_2 but it can be used to monitor and prevent hypoxia and hyperoxia. Different saturation monitors calculate saturations in different ways resulting in nonequivalence of readings between monitors (for example Nellcor monitors yield saturation values on average 2% higher than Ohmeda (now GE Healthcare) monitors).

In the first week of life over 95% of healthy term newborns have oxygen saturations between 92 and 100% whilst breathing regularly in room air and median baseline is over 97%¹³. Studies looking at healthy preterms (30-36 weeks' gestational age) in the first week of life have also shown normal baseline saturations to be high with 95% of infants having baselines between 95.5%-100% during regular breathing¹⁴.

Well premature infants (25-36 weeks at birth) demonstrate median baseline saturations of 99.4% at discharge from the neonatal unit¹⁵. A reasonable safe approach therefore in the CLD population would be to aim for "normal" saturation targets once the risk of retinopathy of prematurity has passed. This applies whether an infant is in air or in oxygen. The practice in Liverpool is to increase saturation limits to 94% and above at postmenstrual age of 32 weeks and in CLD to aim for saturations of 95% and above. One disadvantage of this approach is potentially increasing the total duration of oxygen therapy. In Liverpool, the median duration of home oxygen required after discharge is six months. Compared to some centres the authors' unit uses home oxygen more frequently and discharges at a younger age. However this approach has been shown to be similar to a more restrictive use of home oxygen, in terms of readmission rates, morbidity and total cost of care¹⁶.

Assessment for discharge

There are no national guidelines for discharge criteria for babies on home oxygen and local practice varies considerably. All infants who are clinically stable and likely to need oxygen for more than two to three weeks should be considered for discharge on home oxygen (**FIGURE 1**). A neonatologist or respiratory paediatrician in conjunction with the multidisciplinary team usually makes this assessment. There should be no other



FIGURE 1 Infant receiving home oxygen.

clinical or social issues precluding discharge and local unit discharge criteria must be met. As already discussed, arterial PaO_2 is not an appropriate measurement in this setting and therefore discharge assessment must be made using pulse oximetry.

Most infants will be feeding orally by breast or bottle, although some babies still requiring feeding by gastric tube can be discharged with appropriate support. Multidisciplinary team planning and close cooperation with parents/carers is essential.

At Liverpool, infants requiring oxygen who are clinically stable but yet to establish breast or bottle feeding are prepared for discharge by having the frequency of routine monitoring reduced. ECG monitoring is discontinued completely. Oxygen saturation monitoring is performed for a minimum of four continuous hours on a weekly basis. This period includes time spent awake, asleep and during feeds. The infant is observed during this time by the nursing staff with documentation of activity state, saturations and heart rate. Once oral feeding is established, saturation monitoring is performed to assess supplemental oxygen requirement for discharge home if social circumstances permit. At present formal computer analysed oxygen saturation recordings are not routinely performed prior to discharge although, resources permitting, these would probably be useful. A pragmatic approach is adopted and continuous oxygen therapy is given even if saturations only drop during feeding or sleep.

Successful discharge requires careful selection of families whose social

circumstances will enable them to care for their baby on oxygen at home and who can develop the confidence to do this. If there are concerns about social or domestic circumstances, a home visit by one of the community team may be appropriate.

The neonatal team provides resuscitation training prior to discharge. Parents/carers have several meetings with the home oxygen nurse specialist as part of an educational programme. The aim is to ensure understanding and confidence in the use of equipment and safety issues. Advice is given regarding safe positioning and storage of oxygen delivery systems, the avoidance of smoking and exposure to naked flames, not forgetting birthday cake candles! The oxygen supply company also discusses the use of equipment and storage at the time of installation.

The details of which authorities need to be informed (see **TABLE 2**) and financial aspects such as disability living allowance (DLA) and reimbursement of electricity costs of running the oxygen concentrator are discussed. All infants on home oxygen should qualify for DLA and further financial assistance may be available for families on income support. The inclusion of social workers in the multidisciplinary team is helpful in this area.

Prior to discharge, parents/carers are encouraged to spend time with their baby in the parent room increasing confidence and allowing them to get used to caring for their baby on oxygen without monitoring. Overnight stay in the parent room is encouraged.

Unit practice is to discharge infants at the beginning of the working week in order to optimise the number of support visits. The neonatal community team provide the initial home support until the first outpatient review in the Chronic Lung Disease of Prematurity clinic, which takes place within 10 to 14 days of discharge. Subsequently, the clinical nurse specialist, who also provides telephone advice and support, carries out home visits. All infants have open access to the children's hospital. If the first outpatient review is satisfactory, infants are then reviewed at three to four weekly intervals, either in the Chronic Lung Disease of Prematurity clinic or at home by the clinical nurse specialist.

How home oxygen is supplied

In England and Wales, home oxygen was previously mainly prescribed by general practitioners and provided through local

- General practitioner
- Health visitor
- House Insurance Company
- Motor Insurance Company
- Fire authority
- Electricity supplier (usually informed by oxygen supply company)
- Fire authority (oxygen supply company will automatically contact the local fire services)

TABLE 2. Authorities to be notified prior todischarge on home oxygen.

pharmacies. In February 2006, this was changed to hospital based prescribing with provision through one of four oxygen supply companies (Air Products, BOC, Allied Medical and Linde), which vary according to region. Once a decision is made to discharge an infant with home oxygen, the Home Oxygen Order Form (HOOF) is completed. The Home Oxygen Consent Form (HOCF) is filled in allowing information on clinical diagnosis and oxygen requirements to be shared with the oxygen supplier, primary care trust and home care team.

Flow rates, length of time of administration required per day and method of administration are detailed on the HOOF, and the oxygen supply company then decides on the most appropriate oxygen delivery system (usually an oxygen concentrator as described below). Using the HOOF, arrangements can also be made for visits to other areas of the UK, for example staying with relatives or for holidays.

Most infants will require relatively low flow rates and the most appropriate device is an oxygen concentrator. This uses room air to provide an oxygen supply and is powered by electricity. Costs of electricity are reimbursed; the oxygen supply company will inform the electricity supplier to arrange repayment for electricity use. Parents need to contact the electricity company to ensure priority during electricity cuts.

Oxygen concentrators make some background noise and are therefore not normally fitted in the bedroom. Sufficient non-kinking tubing is provided to reach other areas of the house.

The oxygen supply company installs equipment in the home and provides further training on its use and is responsible for maintenance and equipment failures. Parents are provided with 24-hour emergency contact numbers. Emergency cylinders are provided in case of electricity or equipment failure.

Ambulatory oxygen

The family are supplied with portable oxygen in the form of small cylinders, which can be carried in the car or pram/buggy. Families are given individual advice on expected duration of cylinders at different levels according to their infant's flow rates. Parents should be advised regarding the safe stowing of oxygen cylinders in the car. This should prevent both accidental displacement of cannulae or tubing during routine travel and also ensure secure fastening of the cylinder in case of emergency braking or a road traffic accident. The motor insurance company must be informed that oxygen will be carried in the vehicle.

Withdrawing oxygen

The duration of home oxygen requirement will vary between infants, however most will have oxygen successfully discontinued by twelve months after discharge¹⁷⁻¹⁹. Other diagnoses should be considered if withdrawing oxygen proves difficult. As with discharging infants on home oxygen, there is a lack of evidence on which to base guidelines for withdrawing home oxygen and a wide variety of practice is evident in the UK².

Managing and monitoring oxygen withdrawal can usually be carried out at home and does not necessitate admission. More frequent monitoring may be required during the period of oxygen withdrawal, however this can generally be carried out during home visits from the community team and does not require a saturation monitor to be left in the home except for overnight saturation studies.

There is no evidence to suggest whether it is better, after a saturation assessment, to withdraw continuous oxygen completely or to withdraw oxygen during the day to begin with, and then after further assessing oxygen saturations in air at night time, complete the withdrawal. The practice at Liverpool is to gradually increase the amount of time spent in air during the day. Infants who are clinically well (no significant respiratory distress, no recurrent wheeze or infections), gaining weight and whose oxygen requirement is stable at less than or equal to 0.5L/min are monitored in air during a home visit. Saturations should ideally be monitored whilst the infant is awake, asleep, and when feeding. It has

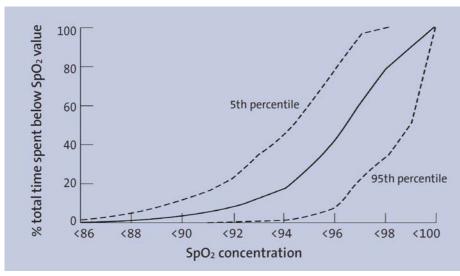


FIGURE 2. Saturation profiles in healthy preterm infants²⁷.

been shown that most infants reach lowest saturations within forty minutes of starting a two-hour room air challenge²⁰. If room air challenge is successful, infants will come out of oxygen for one to two hours each day, this time being progressively increased over the following weeks according to individual response.

Prior to discontinuing oxygen overnight, a formal saturation study at night in air is performed. This is carried out once the infant has been in air for twelve hours during the day for a period of three to four weeks. A saturation monitor is left with the family at home overnight and collected the following morning. Data is analysed in the respiratory unit and presented as a cumulative frequency graph where the infant's saturation profile is compared against the 50th and 5th percentiles (**FIGURE 2**). If the overnight study in air is satisfactory, oxygen is then withdrawn completely.

During the period of oxygen withdrawal, parents are asked to observe their child for signs of respiratory distress, becoming pale or tired and episodes of cyanosis. Appropriate advice is given in case any of these problems occur.

Following successful withdrawal from oxygen, the equipment is not removed from the home for two to three months, in particular in the winter, to ensure that the infant can cope with viral infections without requiring supplemental oxygen. These steps ensure parent/carer confidence and minimise delay should oxygen therapy need to be recommenced.

Infections

Healthcare service utilisation in babies with CLD requiring home oxygen is increased. Infants with home oxygen have been shown to have more frequent and longer readmissions to hospital. Up to 80% of infants on home oxygen will require readmission to hospital in the first two years of life²¹. Most of these admissions are due to respiratory symptoms caused by viral upper respiratory infections and bronchiolitis²².

The risk of nosocomial infection is removed by discharge home but advice

should be given to avoid contact with persons outside of the home who are unwell. Routine childhood vaccination schedule is followed and influenza vaccination is also advised (normally arranged by the General Practitioner).

Palivizumab is a monoclonal antibody treatment licensed for use in babies born at less than 35 weeks' gestation which reduces the risk of hospital admission with respiratory syncitial virus (RSV) positive bronchiolitis. Local policy varies according to which infants receive palivizumab. The practice at Liverpool is to offer palivizumab injections (five monthly injections over the RSV season) to those infants who are still receiving continuous oxygen at the beginning or during the RSV season. Monitoring local virus isolation data from the children's hospital assesses continuing requirement for its use. Injections are given every four weeks and coincide with the home oxygen clinic to avoid duplicate hospital visits.

Nutrition

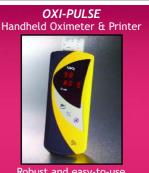
Nutrition plays a major role in both the pathogenesis and management of CLD. Infants with intrauterine growth restriction are particularly vulnerable to CLD suggesting significant antenatal risk factors exist²³. Essential nutrients such as fat stores, trace elements and vitamins are acquired during the last trimester of pregnancy. Babies born prior to this are therefore at risk of deficiencies of essential fatty acids, fat-soluble vitamins and trace elements.

Anti-oxidant enzymes levels are low in very low birthweight infants and this will be compounded by deficiency of trace element cofactors. Anti-oxidant enzymes are crucial in limiting the damage caused by free oxygen radicals produced by hyperoxia, infection and lung injury^{24,25}.

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Infants with established CLD are at high risk of malnutrition and failure to thrive due to increased metabolic demands and reduced intake. Feeding difficulties such as gastro-oesophageal reflux and vomiting are common and can result in decreased energy and nutrient intake. Inadequate nutrition can prolong oxygen dependency and delay resolution of CLD. Infants are capable of producing new alveoli until approximately two years of age and there is some evidence that good somatic growth is a prerequisite for this.

Oxygen saturations should be optimised to ensure good weight gain. When oxygen is discontinued inappropriately, weight gain is reduced⁸. Even if infants are only hypoxic during sleep, weight gain may be reduced²⁶.

Satisfactory growth is one of the discharge criteria and careful attention is paid to energy intake. After discharge on home oxygen, the respiratory nurse specialist measures the infants' growth parameters regularly during home visits. The home oxygen clinic is multidisciplinary and includes input from a paediatric dietician. Further multidisciplinary involvement may be required for example from speech and language therapists if more complex feeding difficulties and behaviours exist.

Conclusion

Long term supplemental oxygen therapy is now established in the management of CLD. In stable infants, home oxygen therapy offers major benefits in parentinfant bonding and providing a normal stimulatory environment for development. Much debate continues around optimal saturation targets, timing of discharge and appropriate withdrawal of home oxygen. In the absence of uniform guidelines a pragmatic and consistent approach locally makes discharge on home oxygen a safe, beneficial and cost effective option.

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