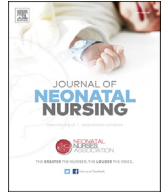




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Management of chronic lung disease infants in the community



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ABSTRACT

The aim of this study is to review the current home oxygen weaning programme used in the past 6 years by the Community Neonatal Nurses, in order to improve or maintain current practice. The study was done retrospectively, by reviewing data of infants discharged from the neonatal unit based in London, United Kingdom and weaned off oxygen by the Community Neonatal Nurses. At least 65/108 (60%) infants were weaned off home oxygen within the 1st year of life.

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Introduction

Accordingly, around 85 000 people in England have home oxygen therapy, making it an average of 600 patients per primary care trust (now known as CCG) and only 4% are children (Primary Care Commissioning, 2011). Evidently, having home oxygen therapy costs England about £110 million each year, sadly at least 1/3 of the people with home oxygen therapy equipment do not use it (Primary Care Commissioning, 2011). Subsequently, since the introduction of the HOOF (home oxygen order form) in February 2006, there has been a drive to ensure secondary care health professionals are the main prescribers, as they tend to review these patients more often within a hospital or clinic setting (Wedzicha and Calverley, 2006). Primary care health professionals (with the knowledge and skills to do home oxygen therapy assessments) can also prescribe home oxygen therapy via the HOOF. It is important to note, that regardless of the way home oxygen therapy is ordered within the secondary or primary care it will continue to be funded by the Primary care services (CCG) (Wedzicha and Calverley, 2006). Indeed, the annual expenditures for home oxygen therapy in the UK and other countries including United States of America, tend to exceed the national budgets (O'Donohue and Plummer, 1995). It can be seen from the above analysis that without oxygen therapy, the medical costs of these patients would be greater, with increased

mortality and reduced quality of life (O'Donohue and Plummer, 1995).

The role of the community neonatal service was established to reduce length of stay, by discharging infants' early on home oxygen, with a diagnoses of chronic lung disease or any other nursing issues. Chronic Lung Disease/Bronchopulmonary Dysplasia is defined as "continued use of supplemental oxygen or respiratory support at 36 weeks post menstrual age" (Balfour-Lynn et al., 2009; Ambalavanan, 2014). In addition to, Balfour-Lynn et al. (2009) and Ambalavanan (2014) definition the Badger System used by nearly all neonatal units in England to record all activity of the neonate stay on the neonatal unit, also identifies chronic lung disease as requirement of oxygen for more than 28 days of life. The above definition was also agreed by a group of health care professionals at the National Institute of Child Health and Human Development (NICHD) work shop in 2000, that chronic neonatal lung disease/BPD is a continues requirement for oxygen during the first 28 postnatal days among infants less than 32 weeks gestation (Britton, 2012). Although Balfour-Lynn et al. (2005) elaborates it as chronic neonatal lung disease with need of supplemental oxygen at various postnatal or postmenstrual ages, mostly affecting 10% of infants born less than 1500 g and premature. Therefore, the use of home oxygen therapy should be administered in non – emergency situation, in order to

1. To reduce or prevent pulmonary hypertension
2. To reduce airway resistance and promote growth

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- To reduce associated risk of sudden unexplained death in infancy (Balfour-Lynn et al., 2009; McMorrow and Sweet, 2013).

Conversely, the [National Guideline Clearinghouse \(2006\)](#) defines non-emergency oxygen therapy as an administration of oxygen at concentrations greater than that in ambient air, with the intent of treating or preventing the symptoms and manifestations of hypoxia. To be able to understand these definitions, the use of home oxygen can be summarised as a therapy used to decrease the work of breathing by increasing alveolar oxygen tension (GOSH, 2016).

It is important to note, that the benefits of discharging a baby on home oxygen therapy, would be

- Reduced hospital length of stay
- Improve the quality of life and psychological impact for infants, parents and the rest of the family
- It is cost effective, as it reduces the cot space capacity on the Neonatal Unit
- Family friendly, minimum equipment within the home setting (Balfour-Lynn et al., 2005; MacLean and Fitzgerald, 2006).

Objective

The aim of this study is to review the current home oxygen weaning programme used in the past 6 years by the Community Neonatal Nurses, in order to determine how infants were successful weaned off home oxygen therapy before the age of 1 year. Secondly, to determine the percentage of infants discharged on home oxygen therapy that failed the current weaning programme and were handed over to the children's home care team. Final, to produce a current evidence based home oxygen weaning programme that could serve as a potential best practice for all community neonatal teams/children's home care teams to adapt within their nursing services.

Method

The study was done retrospectively, by reviewing the data collected through the community neonatal home oxygen data records and annual community reports over the last 6 years, of all infants discharged from the Neonatal Unit with home oxygen therapy. Unfortunately, due to minimum access to the Children

Home Care Team records, the study only collected data about weaning off home oxygen therapy for the infants that would have been under their follow up service. The author set a data collection form with specific questions for example, the gestation age of the infants, date of birth, date of discharge etc. (Please see [Figs. 1–4](#)). The set questions for the data collection form were identified through a literature review via different scholar internet databases. The questions were piloted for their validity and reliability through using data from previous years before the community neonatal service was established. The data was analysed focusing on different aspects of the data collection 1. Number of infants weaned off oxygen within the 1st year 2. Number of infants discharged from the neonatal unit on home oxygen therapy and follow up by children home care team/community neonatal nurses 3. The gestational age at birth 4. Length of days on low flow oxygen.

Results

Accordingly, in the years' 2005 to 2009 a mean of 10 infants per year were discharged from the neonatal unit, with follow up nursing support from the children's home care team. However, when the community neonatal service was established in 2009, in the years' 2010 to 2015 a mean of 18 infants were discharged from the neonatal unit, with 62.5% followed up by the Community Neonatal Nurses and 32.6% followed up by the children's home care team because the infants lived out of area. As a result, only 9.6% were handed over at a year old to the local children's home care team after failing the community neonatal service home oxygen weaning programme.

Evidently, 17.3% infants under the community neonatal nurses were weaned off oxygen within 2 months of Neonatal Unit discharge. At least 28.8% infants under the community neonatal nurses were weaned off oxygen within 4 months of Neonatal Unit discharge. Thirdly, 6.7% infants under the community neonatal nurses were weaned off oxygen within 6 months of Neonatal Unit discharge. Lastly, 9.6% infants under the community neonatal nurses were weaned off oxygen within 12 months of Neonatal Unit discharge. To sum up, over 62% infants were weaned off oxygen before a year old.

Discussion

The results of our study indicate that by having a community neonatal team, there is immediate reduction of hospital length of

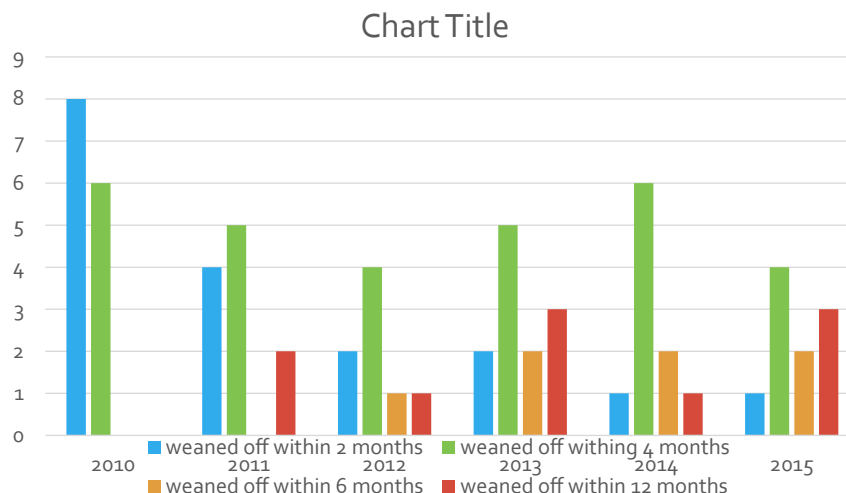


Fig. 1. Weaned off oxygen within the first year.

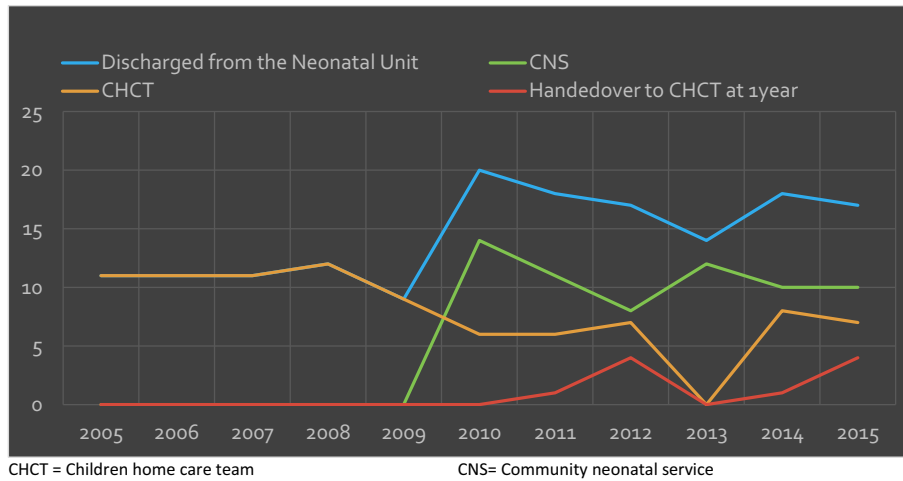


Fig. 2. Involvement of community nurses.

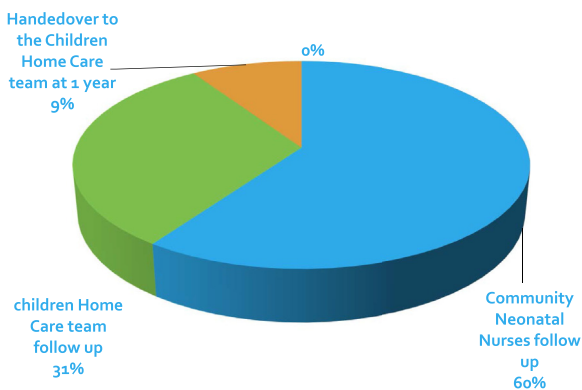


Fig. 3. Infants discharged from the neonatal unit on home oxygen.

stay for infants on low flow oxygen therapy. It is a fact that due to the increasing survival rates of extreme premature babies, this may result in a larger group of infants being discharged with home oxygen therapy in the near future (Greenough et al., 2002). The study by Walston et al. (2011) based on the provision of Community Neonatal Service of all 183 Neonatal Units in England. Found that 85% of all Neonatal Units in England were in agreement that in

order to facilitate early discharge of infants, it would be beneficial to establish a community team within the Neonatal service (Walston et al., 2011). Although, Dixon et al. (2011) study results identify the benefits of early discharge as a way to improve flow, create cot space and decrease the nursing resources on the Neonatal Unit. In comparison to the review by Cherian et al. (2014) that highlights home oxygen therapy as a treatment that promotes closer parent-infant bonding, facilitate reduced hospital length of stay for a stable preterm infant who no longer requires a hospital environment and in addition would be a financial benefit to the health care system by a cost saving of £18000 per infant. The early discharge of an infant on home oxygen therapy has been reported by parents as feeling a of a more normal family life (Cherian et al. (2014).

Our study results did identify that a total of 62.5% of infants were weaned off home oxygen therapy before 12 months of age and this was achieved by using the ‘room air challenge’ as the first trial. According to Cherian et al. (2014) the ‘room air challenge’ starts from half an hour of discontinuation of home oxygen therapy and if saturation is maintained above 96% then a more structured challenge is continued. (Please see Table 1) Furthermore, Cherian et al. (2014) points out that there are factors to consider before starting the home oxygen weaning programme this would be the infants’ respiratory status, infant growth, overnight pulse oximetry results and echocardiography if pulmonary hypertension is present.

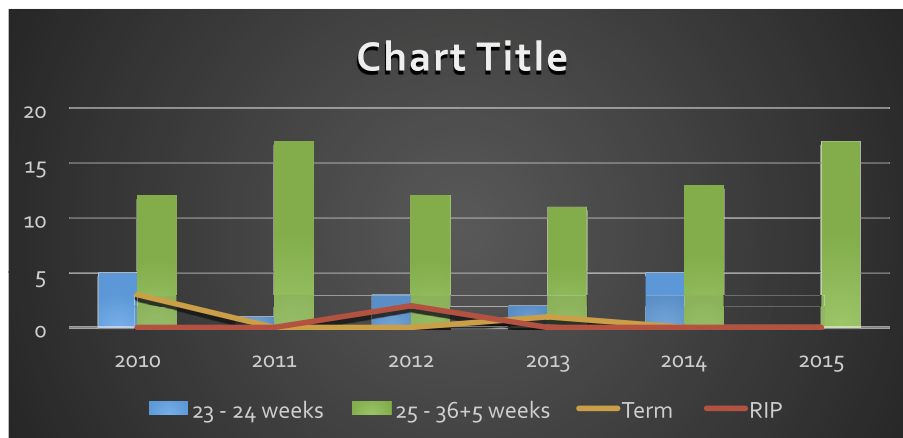


Fig. 4. Gestational age at birth.

Table 1
Home oxygen weaning programme.

1st week of oxygen weaning	30 min off twice daily
2nd week of oxygen weaning	1 h off twice daily
3rd week of oxygen weaning	2 h off twice daily
4th week of oxygen weaning	4 h off once daily
5th week of oxygen weaning	6 h off once daily
6th week of oxygen weaning	8 h off once daily
7th week of oxygen weaning	10 h off once daily
8th week of oxygen weaning	12 h off once daily
9th – 12th weeks of oxygen weaning	Perform overnight oximetry studies (Sleep study)

Indeed, there is a great need to have Community Neonatal Service to follow up infants discharged with home oxygen therapy as it has proved to reduce length of stay on the neonatal unit. The findings of [Walston et al. \(2011\)](#) study that at least 55% neonatal units in England did not have specialist neonatal community nurses, showed lack of consistency across the Neonatal Networks, 19% neonatal units were being supported by paediatric teams and 39% of the neonatal units that had a specialist neonatal community service, had problems with staffing the service. According to the NICE (2010) commissioning assessment of special care cot costs £476 per baby per day verses a cost savings through early discharge for the total 135 days £64260.00 (cited by [Bathie and Shaw, 2013](#)). Inherently, a study by [Lagatta et al. \(2013\)](#) based on 1286 infants discharged on home oxygen therapy in United States of America identified the median hospital length of stay for extremely preterm infants was a range of 97 days (IQR, 79–115 days). However, for the term infant with PPHN and MAS hospital length of stay was 14 days (IQR, 9–18 days) ([Lagatta et al., 2013](#)). Surprising, in our study only three term infants were discharged on home oxygen therapy in 2010 and one term infant in 2013 compared to [Lagatta et al. \(2013\)](#) study that had 250 term infants (at least 19%) discharged on home oxygen therapy.

Therefore, the review by [Cherian et al. \(2014\)](#) highlights the achievement neonatal services have done since 1976, whereby six infants diagnosed with chronic lung disease were successfully treated with supplemental oxygen at home following early discharge from a neonatal unit. According to [Cherian et al. \(2014\)](#) facilitating early discharge on home oxygen therapy requires a combination of clinical assessments and overnight pulse oximetry recordings especially during the infant's vulnerable times following feeds and during REM sleep when they are more hypoxic.

Evidently, in 2010 once a community neonatal nurse was employed within our hospital there were 20 infants discharged on home oxygen therapy, double compared to the previous years before the role was established. There could be an argument of does this only benefit the neonatal unit-cot space availability and financial savings. Similarly, research done by various organisations including Bliss Baby Charity and POPPY Report has found that once an infant has been admitted to the Neonatal Unit, it is a huge cost to the family. A study by [Ballantyne et al \(2014\)](#) based in Canada focused on the perspective of mothers and health care professionals on attendance to Neonatal follow up and in contrast, [Raffray et al. \(2014\)](#) study was based in Colombia explored the health professionals' perspective of the barriers to prepare families for infant discharge from Neonatal Unit. Although, these two studies were from different parts of the world, the findings were similar that mothers would not visit their infant on the neonatal unit or attend clinic, due to short maternity leave (mostly 3 months), insufficient money, transportation costs or child care costs of other children ([Ballantyne et al, 2014](#) and [Raffray et al., 2014](#)). Therefore, the drive would be to move certain services especially oxygen therapy in infants into the home setting. NMC:

The Code (2015) 2.3 states we need to encourage and empower patients/carers to share decisions about treatment or care. In addition to, the above statement parents are encouraged to immediately contact the community neonatal team if concerned about their infant anytime between 9am and 5pm (Monday to Sunday), however in emergency to dial 999.

Accordingly, when the infant is discharged on home oxygen therapy only the named nurse can make any changes in increasing/decreasing the oxygen flow e.g 0.1 l/min to 0.2 l/min. Currently, under the English rules infant's home oxygen therapy is prescribed via the HOOF Part B (home oxygen order form), therefore giving a few health specialist professionals accountability in the decision-making process. The NHS National Home Oxygen Safety Committee in 2015 agreed that a Home Oxygen Initial Risk Mitigation Form (IHORM) and Home Oxygen Consent Form (HOOF) should be completed before any home oxygen is ordered or changes made ([Channon and Bisset, 2016](#)). According to the NHS National Home Oxygen Safety Committee the aim for this process was to raise awareness with the patient/main carers of the risks of having oxygen at home, and this would ensure the health professional takes responsibility whether the risks were low enough to request oxygen for the patient ([Channon and Bisset, 2016](#)). The HOOF should be recognised as a form of medication chart meaning if any changes to the flow rate, it would need to be re-prescribed and oxygen requirement above 0.5 l/min then oxygen concentrator will need to be ordered replacing the cylinders this is only done within the infants setting and could differ for the adult's community settings.

The home oxygen weaning programme used in our study was created to tailor the needs of the infants discharged from the local neonatal unit. Evidently, practices vary in every clinical and community settings' in regards to home oxygen weaning methods, however [Cherian et al. \(2014\)](#) states that whichever method health professionals decide to use, it is essential to constantly review the infant. It is important to note, that the most common method used when weaning off oxygen being sleep study monitor/overnight pulse oximetry.

There is also, a further point to be considered that there are times community neonatal nurses would be unable to wean off the infant off oxygen. This should be escalated early to the infant's named consultant during their outpatients visits then further assessments/investigations would need to be performed to rule out any other medical problems e.g ENT (ear, nose or throat, respiratory or cardiac). Although, for some infants it will be just a matter of 'time', meaning may need longer than a few weeks or months, to wean off oxygen.

At times, parents tend to be very anxieties especially when health professionals diagnose their infant with chronic lung disease and plan for hospital discharge with low flow oxygen. Parental anxieties can be reduced by giving emotional support and explaining to the parents that chronic lung disease slowly improves as healing occurs and lung growth continues as the infants grows ([Zanardo and Freato, 2001](#); [Adams and Stark, 2015](#)). Conversely, the drive to facilitate early discharge from the neonatal unit, could be considered as cost effective, family friendly and importantly, enhances the parent's quality of life ([MacLean and Fitzgerald, 2006](#)). Having considered home oxygen therapy as a significant part to facilitate early discharge from the neonatal unit, it is also reasonable to look at it as a step away from 'separation and marginalisation' of the parents ([POPPY Steering Group, 2009](#)). Certainly, research has improved the relationships between parents and health professionals within the neonatal unit settings allowing more time and parental participation, however we can defiantly agree that the hospital is still not home. Therefore, once the infant is medically fit for discharge, provision and support should be made for the infant and family according to the local guidelines to

facilitate early discharge and follow up until infant has completely weaned off home oxygen therapy.

Conclusion

The role of the community neonatal nurse should be considered in every neonatal unit to reduce the length of stay, however there is an emphasis of having clear home oxygen weaning guideline as a matter of priority. Sleep study monitors should be used as a guide to wean off oxygen, not take the role of the nurse/doctor within the assessment process. The home oxygen weaning guideline used in this study, reduced parental anxieties by involving them in the assessment process from the neonatal unit discharge until the weaning programme was completed. Evidently, practices vary in every clinical and community settings' in regards to home oxygen weaning methods, however Cherian et al. (2014) states that whichever method health professionals decide to use, it is essential to constantly review the infant. The recommendation would be to trail this oxygen weaning programme at a larger sample size gathering data from children's home care teams, respiratory nurse specialists and community neonatal services. In order, to identify if by using a set guideline nationally, would allow uniform working across the children's services within the community settings. Undoubtedly, infants would have better outcomes regardless of which area they cared for, due to the universal standards set through the guideline. The advantages of having a home oxygen weaning programme that ensures infants are off oxygen before their 1st birthday, can be cost savings to the primary care services, because the costs from the oxygen company are based on provision, not usage (Primary Care Commissioning, 2011). Therefore, when professionals do not remove the unused home oxygen equipment, costs are then incurred (Primary Care Commissioning, 2011).

Conflicts of interest

None

Ethical statement

Research was approved by the local Clinical audit department

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