Use of home oxygen for children in England and Wales

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ABSTRACT

Background With the introduction of a standardised ordering system in February 2006, the opportunity arose to collect data on children requiring home oxygen in England and Wales. The authors' aim was to determine the incidence and patterns of home oxygen prescribing.

Methods A paediatric home oxygen clinical network and the Children's Home Oxygen Record Database were established. During a 3-year period (February 2006 to January 2009), prescribers were requested to submit copies of the Home Oxygen Order Forms. In addition, anonymised point prevalence data on all patients currently receiving home oxygen in June 2007 were obtained from the four provider companies.

Results *Children's Home Oxygen Record Database*—Forms were analysed for 888 children <16 years (58% boys) with a median age of 4.1 months; 656 (74%) were <1 year. 541 (68%) had a diagnosis of chronic neonatal lung disease; 53 (7%), neurodisability; and 49 (6%), cardiac disease. Order forms were often incomplete, and prescribing practice was variable.
Provider's cross-sectional survey—There were 3338 children <16 years, representing 4% of all patients on home oxygen. Median age was 3.1 years with a peak at 6 months. The prevalence for paediatric home oxygen use in England and Wales was 0.33 per 1000, with a peak of 1.08 per 1000 for those <1 year. Marked regional variation was noted.

Conclusions This is the first national dataset available for children prescribed home oxygen in England and Wales. The study emphasises the need for a coordinated approach to home oxygen prescribing and justifies the recent publication of evidence-based guidelines.

What is already known on this topic

- Home oxygen is an effective therapy for a number of conditions.
- UK guidelines have been recently published, but generally, the evidence base is poor.

What this study adds

- Paediatric use of home oxygen accounts for 4% of all orders in England and Wales.
- The prevalence is 0.33 per 1000, with a peak of 1.08 per 1000 in those <1 year of age.
- There is considerable regional variation in the use of home oxygen.
- Chronic neonatal lung disease is the commonest paediatric indication, with neurodisability and paediatric cardiac disease the next commonest.

The principal aims of long-term oxygen therapy are to prevent harm from chronic hypoxaemia and to improve any related symptoms.[1] Home oxygen is used either to allow patients to be discharged safely from hospital or to improve symptoms or quality of life in children in the community with chronic hypoxaemia. An evidence-based guideline for home oxygen use in children has recently been published.[2]

A new national home oxygen service for England and Wales was introduced in February 2006, which awarded four companies contracts to provide all the necessary equipment for 11 oxygen regions.[3 4] Ordering was done using a standard Home Oxygen Order Form (HOOF), available from the Department of Health and on the British Paediatric Respiratory Society website (http://www.bprs.co.uk/oxygen.html). Home oxygen is an expensive therapeutic intervention, but during the setting up of this service, it became clear that little was known about numbers of children receiving home oxygen or their clinical diagnoses. There was also no system in place to monitor its clinical use. The Children's Home Oxygen Record Database (CHORD) was set up with the aim of assessing the incidence and patterns of home oxygen prescription. In addition, a single time point survey was carried out, with data obtained from all the oxygen provider companies to the British Thoracic Society (BTS) Home Oxygen Database Committee, and the paediatric data have been analysed.

METHODS

Prospective CHORD study

A paediatric home oxygen clinical network was established with a lead clinician identified in each of the 11 regions. Prescribers were requested to obtain consent from parents/carers and to send a copy of the HOOF in to CHORD, for all new prescriptions made in the 3-year period 1 February 2006 to 31 January 2009. If a parent refused consent, anonymised notification was sent to us with the age and diagnostic code only. This was publicised via the British Paediatric Respiratory Society and the British Association of Perinatal Medicine, and it was intended that

the regional oxygen leads would ensure other hospital specialists in their region were aware of the database. It was assumed that with the new centralised system, prescribers of paediatric home oxygen would be hospital paediatricians rather than general practitioners (GPs). Data were entered on to a Microsoft Access database. Missing diagnostic codes were obtained from hospital prescribers or GPs. Ethical approval was obtained (Central Office for Research Ethics Committees (COREC) reference 05/Q1407/190).

Providers cross-sectional survey

After an agreement with the BTS Home Oxygen Working Group, anonymised data recorded from the HOOFs for children and adults in possession of home oxygen on a single day in June 2007 were obtained from all four home oxygen providers in England and Wales. We were unable to validate ascertainment rates, but it was likely to be almost complete. Duplicate data were eliminated, and records on the same patient were combined if the same person was prescribed oxygen for more than one location. We analysed the data for patients aged <16 years only. Diagnostic codes 11 (chronic heart failure) and 15 (paediatric cardiac disease) were combined as cardiac disease, and codes for interstitial lung disease (5) and paediatric interstitial lung disease (12) were also combined. Midyear residential population estimates were obtained for England and Wales for 2007 from the Office of National Statistics (http://www.statistics.gov.uk), and prevalence rates were calculated against the age-matched population. Children's postcodes were matched to strategic health authorities to obtain regional data. Ethical approval was obtained (COREC reference 06/Q0501/21).

RESULTS

Data on oxygen-prescribing patterns including oxygen flows and duration are provided as an online supplement [ADC to enter weblink].

Prospective CHORD study

A total of 905 forms were received during the 3-year period. In addition, we received 66 anonymised refusal notifications. We also received data on 255 children that we could not use—127 HOOFs without consent and 128 untraceable consent forms without HOOFs. In 17 forms, the age at prescription was >16 years, and these were excluded from analysis, leaving 888 children prescribed home oxygen. These included 310 with incomplete data, which ranged from GP name to incomplete oxygen-prescribing data. The median age of the patients at the time of prescribing was 0.34 years (4.1 months), with 656 (74%) <1 year; 58% were male. Due to significant under-reporting, a national incidence rate and regional variations cannot be calculated. Diagnostic codes were eventually available for 98% children, with more than 90% having an identifiable condition, that is, not code 20 "other" (table 1).

Providers cross sectional survey

In total, there were 91 727 records received, and after cleaning-up of data, this meant there were 86 630 patients on domiciliary oxygen in England and Wales during June 2007. There were 3338 (4%) paediatric patients aged ≤15 years and 83 292 (96%) adult patients aged ≥16 years. The median age of the children was 3.1 years (range 29 days to 15 years and 364 days), and the age distribution is shown in fig 1. The overall point prevalence for home oxygen use among children <16 years in England and Wales was 0.33 per 1000 population, with a peak of 1.08 per 1000 for those <1 year (fig 2). Regional data are shown in fig 3 (plus table in online supplement), with prevalence ranging from 0.47 per 1000 in the North East to 0.25 per 1000 in Yorkshire. Only 574 (17%) children had a diagnostic code entered by the prescriber or recorded by the oxygen companies, and of these, 181 were coded as 20 ("other"). One company automatically recorded code 20 if no diagnostic code was given. Thus, only 393 (11%) had a meaningful diagnostic code entered (table 1).

Table 1 Patient details for the commonest diagnostic codes in the prospective CHORD study and oxygen provider's cross-sectional survey

Diagnosis	n (%)	Age, yr	
		Median	IQR
Children's Home Oxygen Record Database (n=888)			
Chronic neonatal lung disease	541 (68)	0.3	0.2–0.4
Neurodisability	53 (7)	5.9	1.7–10.3
Cardiac disease	49 (6)	0.5	0.3–1.2
Interstitial lung disease	24 (3)	0.7	0.3–5.0
Neuromuscular	26 (3)	1.2	0.4–7.5
Oxygen provider's cross-sectional survey (n=3449)			
Chronic neonatal lung disease	171 (44)	1.0	0.5–1.5
Neurodisability	54 (14)	9.2	4.3–12.1
Cardiac disease	33 (8)	2.9	1.2–9.3
Interstitial lung disease	28 (7)	2.8	1.4–7.0
Neuromuscular	20 (5)	4.3	1.9–10.9

No other diagnostic code occurred in more than 3% of the children in CHORD and no more than 5% in the cross-sectional survey. The difference in diagnostic categories between the two databases was significant ($p<0.0001$), using a χ^2 test.

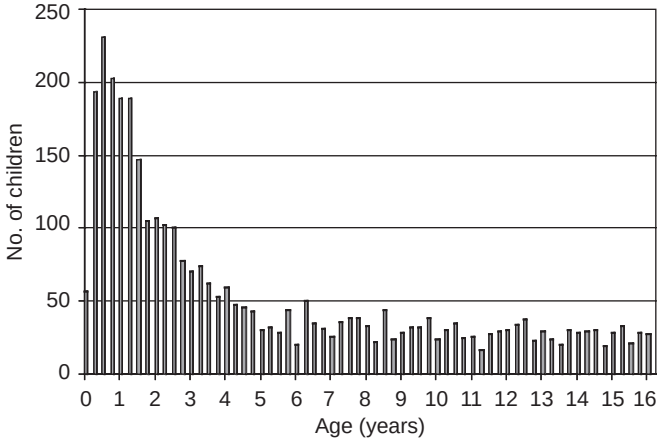

Figure 1 Age distribution of children in England and Wales receiving home oxygen.

DISCUSSION

We have, for the first time, collected national data for England and Wales on the use of home oxygen in children. During the planning of the new centralised home oxygen service, it emerged that healthcare commissioners did not have data on how many children (or adults either) were receiving home oxygen at the time. Undoubtedly, individual companies had their own data but these were not available because of commercial sensitivities during the tendering process; hence, there was no national data. There is in fact very little information published in any country, although there is a Danish Oxygen Register

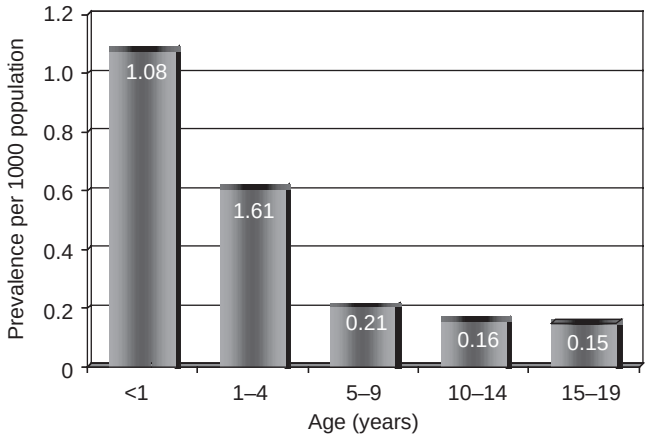

Figure 2 Prevalence by age of children in England and Wales receiving home oxygen. Overall prevalence for children aged 0–16 years inclusive (n=3449) was 0.35 per 1000 population.

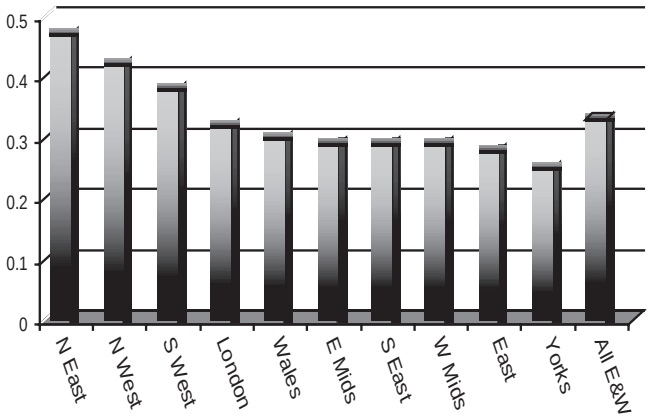

Figure 3 Prevalence by region of children aged 0–15 years inclusive in England and Wales receiving home oxygen. Overall prevalence for children aged 0–15 years inclusive (n=3338) was 0.33 per 1000 population.

with a publication that indicated that 23 (10.5%) of 2190 patients on home oxygen were <18 years old (this compares with our finding of 3.9% patients <16 years in England and Wales).[5] There is also an older Swedish National Register that reported on patients aged 2 to 86 years,[6] and a later publication comparing their results with a Norwegian National Register of domiciliary liquid oxygen.[7]

We now have good prevalence data estimating that 0.33 per 1000 children are oxygen dependent at home at some time. This is a significant group of children (approximately 3.5 thousand) with a major disability. Most are <1 year (prevalence 1.08 per 1000), reflecting the fact that by far, the commonest diagnostic indication is chronic neonatal lung disease. The number of children increases up to a maximum at 6 months of age because below that age, many of the children are still inpatients in neonatal units. Before collecting these data, it was not at all apparent that children with neurodisability were the second commonest diagnostic category receiving home oxygen, and this indication still needs clarifying. The BTS guidelines have suggested that quality of life rather than oxygen saturations should be the main consideration in this group.[2] We also have interesting data on regional differences in home oxygen use, with prevalence highest in the North East (0.48 per 1000) and North West (0.42 per 1000) of England and lowest in Yorkshire (0.25 per 1000). The reason for these differences is not yet apparent, and although it possibly relates to rates of preterm delivery, this warrants further study.

Unfortunately, both our datasets have problems. The provider's cross-sectional study is a comprehensive survey of children who were in possession of home oxygen, but we cannot be certain that they were using it at the time. In addition, the data recorded on the HOOFs were incomplete, with a minority containing diagnostic information and scant information provided on the use of oxygen accompanying home ventilation. This was partly because of poor completion of the HOOFs and partly because some companies did not record all the data. In contrast, the data from the CHORD database are of a high standard in detail but are significantly incomplete in ascertainment. Differences in the proportions of HOOFs received from various regions compared with that expected from the provider's accurate regional data show how dependent CHORD was on willingness of prescribers to participate. It was not felt to be permissible to acquire the HOOF details routinely from the companies without parental consent. At the time of planning, the service we had indicated to the Department of Health that a clinical database was essential and should be a mandatory part of the ordering process, but this was also not possible. It was apparent how badly many of the HOOFs were completed (presumably mostly by doctors), which undoubtedly leads to delays in the companies providing the oxygen to the homes. The HOOF has since been modified slightly and it is planned for there to be an electronic HOOF that may make it harder to provide incomplete information, although only if all fields are made mandatory.

In conclusion, we have surveyed the pattern of home oxygen prescribing across England and Wales and have estimated the prevalence in children by age and region. As expected, we found that the commonest indication was chronic neonatal lung disease, but surprisingly, the second commonest was neurodisability. This survey emphasises the need for a coordinated approach to oxygen prescribing in the UK and justifies the recent publication of evidence-based guidelines for home oxygen prescribing.[2]

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Competing interests The CHORD database was part sponsored by the British Lung Foundation, and Carburos Metálicos (of Air Products) provided funding that allowed BH to work 1 d/wk on the database, in collaboration with IBL at the Royal Brompton Hospital.

Ethics approval This study was conducted with the approval of COREC (reference nos. 05/Q1407/190 and 06/Q0501/21).

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