Ventilator dependency in the United Kingdom

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Abstract

There are 24 children who are currently long term ventilator dependent in the UK. Nine of these are cared for entirely at home. An additional 11 children have been long term ventilator dependent since March 1983. The prevalence of these children appears to be increasing. The financial and manpower resources needed for these children whether at home or in hospital is considerable. There are reasons to suppose that the apparent increase in prevalence will continue.

An attempt has been made to establish the prevalence and incidence of children on long term ventilation in the UK during the period March 1983 to June 1988. These children need considerable manpower and financial support. It is important to know therefore whether the prevalence is increasing by keeping a register of cases notified. This has also been helpful in putting clinicians with similar problems in touch with each other as well as providing a database for further research on the circumstances of the families and their coping ability.

Methods

All paediatricians in the UK were requested through a British Paediatric Association newsletter (March 1983) to notify children who had been on total ventilatory support for six months or more. The paediatricians were circulated again in 1987 for follow up information and for notification of further cases. At this time members of the Association of Paediatric Anaesthetists of Great Britain and Ireland were also contacted. Specific inquiries were made of special centres involved with ventilatory problems.

During the period of study it is probable that increasing numbers of children with neuromuscular disease have been offered ventilatory assistance, for example via a curasse or more lately via a closely fitting face mask, particularly at night. As the dependency needs and rehabilitation potential of these children are somewhat different it was decided not to include them in this study. Details requested included age, date of birth, diagnosis, date when ventilation started, and any additional details such as whether the management was more home or hospital based. For reasons of confidentially the child's name was not requested.

Results

During the period specified 35 children have been notified (a further three who have been notified since this period are not included). Numbers in broad diagnostic categories with sex, distribution, and age range when starting ventilation are set out in table 1. Included within the former group are six children injured usually as a pedestrian during a road traffic accident. Four of these are boys.

Incidence and prevalence of children notified to the study by calendar year are set out in table 2.

Ten children were ventilated mainly at home—including five of those with primary nocturnal hypoventilation. An additional five

Table 1 Diagnosis and numbers of children, sex, and age range

Diagnosis	*No of children*	*Boys*	*Girls*	*Age range when ventilation started*
High cervical trauma*	14	9§	4	0–12 years
Neuromuscular disease†	7	2	5	3 months–2 years
Primary nocturnal hypoventilation‡	6	2§	3	0–3 years
Infection ‖	3	2	1	2 weeks–1 year
Tumour	2	1§		6–10 years
Bronchopulmonary dysplasia	2	2		From birth
Vascular malformation	1		1	From birth

*Includes one non-accidental injury and one birth injury incurred during delivery of an extended breech.
†Consists of three with spinal muscular atrophy, three with congenital myopathy, and one with a congenital myasthenic syndrome.
‡An additional child has nocturnal hyperventilation as a sequel to herpes encephalitis and has therefore been included in the infection category.
§Sex of one of the children unknown.
‖Includes one child with poliomyelitis, one with *Haemophilus influenzae* myelitis, and one with lower brain stem herpes encephalitis.

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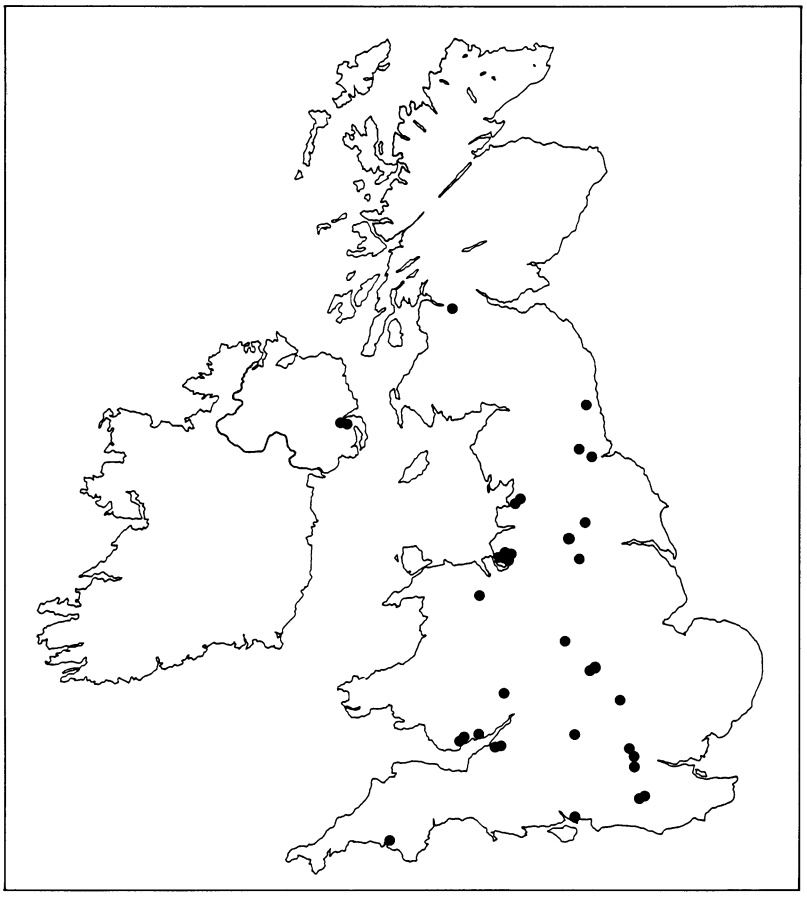
Accepted 13 June 1990

*Table 2 Incidence and prevalence of ventilator dependent children by calendar year**

	1975	*1976*	*1977*	*1978*	*1979*	*1980*	*1981*	*1982*	*1983*	*1984*	*1985*	*1986*	*1987*	*1988*
Incidence	1	0	1	1	1	2	2	2	4	4	2	10	3	0
Prevalence	1	1	2	3	4	6	8	10	14	17	17	24	24	24

*Either the age or the date when starting ventilation are not available for two of the children.



Geographical distribution of ventilator dependent children in the UK during the study.

spent short periods at home. Thus 20 are or have been managed entirely in hospital—usually in intensive care units. The longest period of ventilation from childhood has been 14 years. Seventeen of the 35 have been ventilated for four years or less.

Geographical distribution is shown in the figure.

Nine children have left the register during the study period. One has left the paediatric age range, and two have been successfully weaned from the ventilator after seven and nine months; six have died. Two died from progressive deterioration of their disease, one each had aspiration pneumonia, cor pulmonale, and accidental disconnection in intensive care. One additional child died at home.

Discussion

A case finding study of this nature which is based on voluntary reporting is likely to be an underestimate, the degree of which is difficult to ascertain.

With the exception of 1986, which seems to have been an unusual year, the incidence of ventilated children would seem to have been reasonably constant during the eight years before the end of the study period. Prevalence would appear to have been rising over this time. It is possible, however, that this is an artefact of case collection. Clinicians were asked to notify children under their care at the time. As no attempt was made to collect data retrospectively it is probable that numbers of children were ventilated previously who either died or were weaned from the ventilator before this study started. Alternatively there may be a greater willingness on the part of some clinicians to embark on long term ventilation. Some support for this is given by the geographical distribution, which does not appear to follow closely centres of high population density. A number of children injured were resuscitated outside hospital. Increasing survival if real may in part be due to an increased awareness of resuscitative techniques among the general public.

Children on long term ventilation can be divided into three dependency groups. The least dependent are those children with nocturnal hypoventilation who are ambulant and ventilator independent during the day. Intermediate are those children who have chronic lung disease, who are ventilator dependent by day as well as by night, but who are less physically handicapped. The most dependent group of children have either high cervical cord disease or generalised neuromuscular disease. Although there are children in the intermediate category in the United States (A Goldberg, personal communication), none have as yet been identified in the UK.

The resources required and the stress imposed are clearly determined by the degree of dependency. It is not surprising that five of the six children with nocturnal hypoventilation are managed entirely at home.

Estimation of the financial cost of home ventilation is highly complex. It has been estimated recently in Australia that it requires a capital outlay of approximately £12 500 with an annual cost of approximately £3750.[1] This latter figure is obviously highly variable reflecting the degree of dependency and the need for professional support by the family. It is clearly important therefore that managers responsible for resource allocation need to be aware of the apparent increase in prevalence. It may be argued that funds should be made available either at regional level or from a central fund.

Increasing numbers of young men with Duchenne muscular dystrophy are on long term ventilation both in the United States and elsewhere in Europe. This issue has scarcely been addressed in the UK but may be a further cause for increased prevalence and hence resources. The ethical implications of this area are, like the financial ones, complex. In the debate it should not be forgotten, however, that one of the lessons of the poliomyelitis epidemic was that individuals totally ventilator dependent were, given a positive rehabilitation approach, able to live fulfilled lives, contributing usefully to their families as well as to society in general.

I am grateful to all the clinicians caring for these children who kindly supplied me with details of their patients.

1 Gillis J, Tibballs J, McEniery J, *et al.* Ventilator dependent children. *Med J Aust* 1989;150:10–4.