Home ventilation of a child with motor and sensory neuropathy

Life does have a price, and the rest of us have to pay it

EDITOR,—The article debating whether a child with motor and sensory neuropathy should have been ventilated at home raises many wider issues, besides illustrating how hopelessly unevolved our grasp of moral issues remains.¹ R H Davies does not believe that a person's misery can be measured (though this claim is neatly countered by Ian Harvey), but Davies nevertheless needs to arrive at some system of measurement because other people have clearly paid a price for the expenditure on this child.

The high moral tone of the mother's contribution to the article evaporates when you realise that the price that she claims one cannot put on a child's life will nevertheless be paid—and from someone else's money. Her statement expressly concerns a child's life, but one might ask why a child's life should be more valuable than that of a person outside childhood. The mother's attitude is not unique: pressure groups (currently those for patients with multiple sclerosis and patients receiving renal replacement treatment are prominent) clamour for more resources to be voted to their cause, either unaware or uncaring that the advancement of their cause means the retarding of another group's cause.

Hugh Newton-John describes the phenomenon of "entrapment" in the context of this and similar cases. Are we as a nation now entrapped by the concept of the NHS? Many health authorities, my own included, limit in vitro fertilisation. Couples thus find themselves having contributed through their taxes to a system that

then fails to meet their immediate and pressing need—perhaps the only need they have expressed in their adult life. They are then in the anomalous position that they cannot afford private in vitro fertilisation because they do not have sufficient funds after they have made their contribution, through tax, to the care of people they do not even know.

Finally, is there, to borrow Harvey's term, another "point of indifference"—that at which the morality of providing care for those who cannot afford it is exactly balanced by the immorality of taxing people so hard that they cannot afford to arrange for themselves a service superior to that provided by the state? Are we now at or beyond this point?

FRASER M HADDEN

Consultant in communicable disease control

Suffolk Health Authority,
PO Box 55,
Ipswich IP3 8NN

1 Davies RH, Harvey I, Newton-John H, Ward TA. Home ventilation of a child with motor and sensory neuropathy. *BMJ* 1996;313:153-5. (20 July.)

Central funding and a central resource providing information are needed

EDITOR,—R H Davies is to be praised for the sensitive approach taken in striving to obtain the most appropriate care for a ventilated patient.¹ Undoubtedly those readers who have been in a similar situation will have been reminded of their own experiences and the seemingly endless round of meetings that took place.

In 1993 I undertook a postal survey of members of the Paediatric Intensive Care Society asking about children ventilated at home in Britain. I hoped, forlornly, to organise a meeting of interested parties. I assumed that most children ventilated at home would be known to members. The survey discovered 31 children aged 1-16, living as far apart as Aberdeen and Bodmin, receiving some sort of ventilatory support at home. Sixteen were ventilated only at night. The 15 receiving full time ventilation had suffered inflammatory disease of the central nervous system, cord trauma, or myopathy. The geographical scatter of these children meant that no one centre had great experience of establishing long term, full time domiciliary ventilation.

In 1992 I coordinated the multidisciplinary team that successfully established home ventilation of a 2 year old boy who was apnoeic after transverse myelitis. The child survived for two years before dying of pneumonia secondary to infection with respiratory syncytial virus. Before his discharge, the family home had to be modified, equipment bought, and a team of nurses (care assistants) employed and trained. The capital costs were met by a joint funding arrangement between the health authority and local authority. The nurses were employed by the community trust. These costs were considerably less than those of a paediatric intensive care bed, as Trudy A Ward points out in her article about Davies's case.¹ Discharging this child released what was at the time a quarter of our complement of paediatric intensive care beds.

We went through many stages in achieving our patient's discharge. The idea that he should go home was initially suggested by the parents and

was then supported by all concerned. The drawing up of plans and lists of equipment lists and the training of staff were not unduly delayed: the team was well motivated. Unsurprisingly, funding took months to arrange.

I support Ward's move towards establishing a nationally consistent approach. I believe that the local clinicians should look at the individual requirements of each child, but central funding and a central resource providing information and experience would help us to expedite these children's discharge when appropriate.

IAN BARKER

Consultant anaesthetist

Sheffield Children's Hospital NHS Trust,
Sheffield S10 2TH

1 Davies RH, Harvey I, Newton-John H, Ward TA. Home ventilation of a child with motor and sensory neuropathy. *BMJ* 1996;313:153-5. (20 July.)

Study aims to set up national database of children receiving ventilatory support

EDITOR,—Arranging for children who are dependent on technology to be treated at home is often fraught with difficulties before and after discharge. The decision taken by R H Davies's team to transfer the care of a girl who was dependent on a ventilator from an adult intensive care unit to her own home was one that required a great deal of insight and planning.¹ In many instances, home care for such children is increasingly recognised as best for the child and family.² The comment made by this child's mother leaves little doubt that the decision taken was the right one for this family despite the poor prognosis.¹

A survey of members of the British Paediatric Respiratory Society in 1995 estimated that about 100 children were receiving long term ventilation in Britain, two thirds of whom were cared for in their own home. This is a substantial increase from the number reported by Robinson in 1990.³ The cost of home care, despite Ian Harvey's assertion,¹ is often less than the cost of a prolonged stay in hospital.⁴ Increasingly, purchasers are employing trained carers to deliver individual care at home. No national database of children receiving ventilatory support in Britain is available for reference. A study funded by the Department of Health and orchestrated by a team of interested parties is currently aiming to develop such a database. We also plan to quantify and assess the needs of children currently ventilated long term in NHS institutions who could receive domiciliary ventilation and to formulate guidelines for the provision and coordination of a domiciliary paediatric ventilation service.

France already has a national system for patients ventilated at home and those dependent on oxygen; this is centrally funded by the public health service and provides a uniform, comprehensive standard of care accessible to all. Perhaps this is what Britain should aim for.⁵

We would welcome correspondence from readers who have gained experience in this work or could contribute.

E JARDINE

Research sister

C WALLIS

Consultant paediatrician

Respiratory Unit,
Great Ormond Street Hospital for Children NHS Trust,
London WC1N 3JH

Advice to authors

We receive more letters than we can publish: we can currently accept only about one third. We prefer short letters that relate to articles published within the past four weeks. Letters received after this deadline stand less chance of acceptance. We also publish some "out of the blue" letters, which usually relate to matters of public policy.

When deciding which letters to publish we favour originality, assertions supported by data or by citation, and a clear prose style. Wit, passion, and personal experience also have their place.

Letters should have fewer than 400 words (please give a word count) and no more than five references (including one to the *BMJ* article to which they relate); references should be in the Vancouver style. We welcome pictures.

Letters should be typed and signed by each author, and each author's current appointment and address should be stated. We encourage you to declare any conflict of interest.

Please enclose a stamped addressed envelope if you would like to know whether your letter has been accepted or rejected.

Letters will be edited and may be shortened.

- 1 Davies RH, Harvey I, Newton-John H, Ward TA. Home ventilation of a child with motor and sensory neuropathy. *BMJ* 1996;313:153-5. (20 July.)
- 2 Goldberg AI, Faure EA, Vaughn CJ, Snarski R, Seleny FL. Home care for life-supported persons: an approach to program development. *J Pediatr* 1984;104:785-95.
- 3 Robinson RO. Ventilator dependency in the UK. *Arch Dis Child* 1990;65:1237-9.
- 4 Fields AI, Rosenblatt A, Pollack MM, Kaufman J. Home care cost-effectiveness for respiratory technology-dependent children. *Am J Dis Child* 1991;145:729-33.
- 5 Muir JF, Voisin C, Ludot A. Organization of home respiratory care: the experience in France with ANTADIR. *Monaldi Arch Chest Dis* 1993;48:462-7.

GPs need to be more proactive in providing health care to teenagers

EDITOR,—When asked what type of contraceptive services they want, teenagers say that they want services that are local and that are accessible every day and in an emergency. This type of service is more readily provided by general practice. In addition, general practitioners and their colleagues have the opportunity to discuss health issues in general with teenagers. There is evidence, however, that teenagers receive suboptimal care in general practice and that general practitioners frequently fail to make the most of the opportunities afforded by routine consultations.¹ As Anna Graham and colleagues have found, those teenagers most in need of help and information may be those least likely to receive them.²

Colleagues and I tried to address the problem of teenage health care in a deprived inner city population by running weekly teenage clinics in two general practices in east London over six months. This model has been tried with some success elsewhere, although published reports largely refer to middle class, affluent populations.³⁻⁵ Despite approaching all 13-17 year olds in the practices directly, we achieved only a 7% (63/867) attendance among all those invited. We had greater success when we targeted 15 and 16 year olds and invited them to the clinic for booster doses of tetanus and polio vaccine, achieving an attendance of 12% (43/349), as opposed to 2% (6/262) among those receiving general invitations. Colleagues attempting to run teenage clinics in similarly deprived areas have experienced similarly low attendance (personal communications).

Teenage clinics may therefore not be the answer to improving access to contraception and health care for high risk teenagers. General practitioners may need to be more proactive in routine consultations, allow flexibility in appointment systems, and, above all, ensure confidentiality. We may also need to acknowledge the public health dimension of unplanned pregnancy and be prepared to work in schools and other non-traditional settings, liaising more closely with other agencies both within and outside the health sector.

The most important consequences of unplanned pregnancy among teenagers are socioeconomic rather than medical, and the problem should be addressed at this level. Nevertheless, health professionals, particularly general practitioners, have an important role in health education and the provision of services. With the increasing concern about teenage health, we need to take up the challenge.

NICOLA COWAP
General practitioner

12 Parolles Road,
London N19 3RD

- 1 Jacobson LD, Wilkinson C, Owen PA. Is the potential of teenage consultations being missed? A study of consultation times in primary care. *Fam Pract* 1994;11:296-9.
- 2 Graham A, Green L, Glasier AF. Teenagers' knowledge of emergency contraception: questionnaire survey in south east Scotland. *BMJ* 1996;312:1567-9. (22 June.)

- 3 Donovan CF. Is there a place for adolescent screening in general practice? *Health Trends* 1988;20:64.
- 4 Hibble A, Elwood J. Health promotion for young people. *Practitioner* 1992;236:1140-3.
- 5 Campbell A, Edgar S. Teenage screening in a general practice setting. *Health Visitor* 1993;66:365-6.

Survival of patients initially resuscitated from out of hospital cardiac arrest

Study did not include patients admitted for intensive care

EDITOR,—Stuart M Cobbe and colleagues report their study of the survival of patients initially resuscitated from cardiac arrests that occurred outside hospital.¹ They do not mention the number of patients admitted to intensive care units after cardiac arrest. From the methodology their study seems to have included only those patients admitted to hospital wards. Patients admitted to intensive care units after cardiac arrest require continuing cardio-respiratory support and have suffered greater hypoxic cerebral injury. Inclusion of these patients in the study would have led to a higher incidence of neurological disability and a higher mortality.

I recently carried out an audit of patients admitted after cardiac arrest to the intensive care unit at Auckland Hospital, New Zealand. From the department's database I identified 63 patients as having required admission for intensive care during 1 January 1994 to 31 December 1995. Forty four patients who had had a cardiac arrest outside hospital were admitted to intensive care, of whom 29 died during their inpatient stay. The average age of survivors was 62 (range 28-90) and of non-survivors 59 (37-82). Advanced age was not found to be a bar to survival. Survivors were found to have had a higher initial Glasgow coma score on arrival in hospital.

IAN HATCHER
Specialist registrar

Department of Anaesthesia,
Royal Hallamshire Hospital,
Sheffield S10 3JF

- 1 Cobbe SM, Dalziel K, Ford I, Marsden AK. Survival of 1476 patients initially resuscitated from out of hospital cardiac arrest. *BMJ* 1996;312:1633-7. (29 June.)

Author's reply

EDITOR,—Our study entailed scrutiny of the discharge summaries from every acute hospital in Scotland, and it did not prove practical to obtain information on the time that patients spent in intensive care units. Indeed, the definition of intensive care differed between teaching and non-teaching hospitals. For the purposes of our survey, the phrase "admitted to a hospital ward" meant admission to any hospital ward, whether general medical, coronary care, or intensive care. The phrase was used to identify patients in whom spontaneous circulation returned for long enough for them to be admitted from the accident and emergency unit.

We agree with Ian Hatcher's observations that mortality in patients requiring admission for intensive care is higher than that in patients whose clinical condition is sufficiently stable to allow admission to a coronary care unit or a general medical ward.

S M COBBE

Walton professor of medical cardiology
Department of Medical Cardiology,
Glasgow Royal Infirmary,
Glasgow G3 7ER

Data on eligibility for thrombolytic treatment cannot be generalised

EDITOR,—John K French and colleagues conclude that only about half of patients admitted to coronary care units with definite or probable myocardial infarction are eligible for thrombolytic treatment, with most of the remainder presenting more than 12 hours after the onset of symptoms.¹ This rather low rate of eligibility, based on local data from Auckland, should not be regarded as a universal standard. At Newham General Hospital in east London the data entered prospectively into the coronary care unit's database are very different. Of 1184 patients with definite myocardial infarction in whom the duration of chest pain was recorded, 1120 (94.6%) were admitted within 12 hours of the onset of symptoms, compared with 576 (53.3%) of the 1081 patients in Auckland. This had important implications for treatment, with 869 (73.4%) of our patients receiving thrombolytic treatment compared with 470 (43.5%) in Auckland, although the hospital mortality in Newham was slightly higher (157 (13.3%) v 138 (12.8%).)

There is unlikely to be a single explanation for these differences, but it is reasonable to deduce that patients are able to get to hospital quicker in the densely populated inner city area served by Newham General Hospital than in Auckland. The difference in mortality can probably be attributed to differences in the risk characteristics of the patients. For example, all the patients at Newham General Hospital had definite myocardial infarction (albeit according to slightly different criteria from those used by French and colleagues) and 242 (20.4%) were diabetic compared with 124 (11.5%) of the patients in Auckland.

A more important general point to be drawn from the differences between the two sets of data is that variables such as hospital mortality and the proportion of patients receiving thrombolytic treatment (which threaten to form the basis for hospital league tables in Britain) are often subject to influences beyond medical control and are not, therefore, amenable to simple comparison between units. Certainly, French and colleagues should not assume that their conclusions about eligibility for thrombolytic treatment in Auckland can be generalised to coronary care units in other parts of the world, where local geography and patient populations are likely to be different.

ADAM D TIMMIS
Consultant cardiologist

London Chest Hospital,
London E2 9JX

- 1 French JK, Williams BF, Hart HH, Wyatt S, Poole JE, Ingram C, et al. Prospective evaluation of eligibility for thrombolytic therapy in acute myocardial infarction. *BMJ* 1996;312:1637-41. (29 June.)

Sunscreens, suntans, and skin cancer

Local councils should remove sunbeds from leisure centres

EDITOR,—J M McGregor and A R Young's editorial on sunscreens, suntans, and skin cancer prompts me to make several observations.¹ The worldwide epidemic of skin cancer continues unabated, with reported cases of non-melanoma skin cancer and melanoma at least doubling every 10 years.^{2,3} There is little argument that ultraviolet B radiation is the prime promoter of non-melanoma skin cancer, but there is increasing evidence that ultraviolet A is a promoter of