

Home mechanical ventilation – a logistic and human medical challenge

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In June 1983, when I was a respiratory consultant to a university medical clinic in Geneva, one Friday evening I saw my first-ever patient with advanced Duchenne's disease. Maurice¹ was a 16-year-old obese boy, suffering from severe quadriplegia complicated by respiratory failure. He was febrile and the diagnosis of aspiration pneumonia was easily arrived at, since the boy had practically no swallowing reflex. Despite the fact that Maurice was fully conscious, and perhaps because I was very much impressed by the situation, I did not ask him any questions about his disease – such as his preferences among treatment options and what he expected from life, despite his very severe handicap. On the contrary, and completely arbitrarily, I prescribed antibiotics and told his primary-care physician that “*the best thing for this poor fellow would be an early death*”. The following Monday, to my great surprise, I saw Maurice again. He had been admitted to the intensive care unit during the night, had been intubated and was being mechanically ventilated. My first reaction was anger because the young physician in charge had not followed what I considered to be clear-cut instructions. For the following three months Maurice was ventilated, because weaning from the respirator turned out to be impossible, and I told my colleagues that this confirmed my considered opinion that Maurice should not have been intubated at all, at any time.

At this point Maurice's parents, who had taken care of this quadriplegic boy at home for several years without special support, were becoming increasingly anxious, particularly when they realised that we had no other plans for their child than to wait for a terminal event such as an infection or cardiac complication. Maurice's mother became very aggressive towards us, because she realised that during these three months we had undertaken no research into her son's problem, such as contacting more experienced physicians in the field of advanced neuromuscular disorders. In response to the parents' pleas, but without much conviction, I contacted a number of experts in France whose names I had found in the medical literature. I was quite surprised to learn that, in the view of these colleagues, there was no doubt that Maurice should be tracheostomised and placed on home

mechanical ventilation – a possibility that we had not even considered up to that time.

With some degree of scepticism we proceeded as directed by our French colleagues, and it was the start of an adventure that was a source of both fulfilment and enrichment. To begin with, this first home mechanical ventilation in Geneva forced us to tackle many logistic, financial, technical and human issues which, through the solutions found, proved highly useful in caring for subsequent similar patients. Second, we had the opportunity and the great pleasure of caring for Maurice, who became a friend during the following nine years until his sudden death, from cardiac arrhythmia, at the age of 25. After frequent discussions with Maurice and his family we became convinced that, if faced with the same decision again, he and his close relatives would opt for tracheostomy and home mechanical ventilation. I am in no doubt as to the strength of their conviction.

Personally, I have learned a great deal from the story of Maurice. First, I realised how complacent an ignorant physician can be, and indeed it was my last chance to learn some modesty. Second, I realised how far a family's love can reach in day-to-day care of a severely disabled member, over several years and in difficult circumstances. During the last years of Maurice's life, mechanical ventilation was practically continuous, 24 hours daily. Finally, I have understood that a patient's quality of life may remain satisfactory even in the worst physical situation. I never doubted that Maurice was happy to live with his parents, in spite of his condition as a quadriplegic, fully dependent person.

In this issue of Swiss Medical Weekly, Kamm and colleagues (page 261) make an important contribution to our knowledge of the paediatric patient population who benefit from home mechanical ventilation [1]. The authors have collected, for the first time in Switzerland, a maximum of information about children ventilated at home. Importantly also, we will for the first time be in a position to assess the needs of these patients and of their families. Of course, the task is by no means finished, and every effort must be made to complete and update a nationwide survey which should be conducted at least annually. As in other countries, it is necessary to assess whether or not the

¹ Name changed for reasons of confidentiality.

relatives of these children receive adequate support in doing their extremely demanding job. This can only be determined by awareness of the existence of such patients and analysis of their specific needs [2–4].

A survey has already been undertaken in Switzerland for adults, and the first report was published in 1989 [5]. By the end of 1999, more than 300 patients were registered in a survey covering the whole of Switzerland. The patients are chiefly adults under non-invasive mechanical ventilation, administered by nasal mask; these data are drawn from the registry maintained by the Swiss Lung Association, which has developed guidelines for physicians interested in this technique [6]. In addition to the task of recording data, the Swiss Lung Association is also concerned with refund of the costs involved in home mechanical ventilation and operates a form of quality control of the technology used and its indications. The first advance was to ensure that funding of home mechanical ventilation could be negotiated with the insurance companies and in particular with a national reinsurance company. A second step was designation of a panel of experts to review all indications. These experts' agreement became a prerequisite for refund of home mechanical ventilation, which is granted only if the guidelines are respected.

Even if the patients for whom an indication for home mechanical ventilation exists are not very numerous, their lives involve such suffering, either

for their relatives or themselves, that they must be identified and helped. We ourselves, as care providers, have much to learn from these patients and their families. Almost daily they show us particularly impressive examples of courage and abnegation. Moreover, their difficult situation raises ethical concerns regarding the prolonging of life in patients with severe physical limitations; these thorny, but essential, problems must be solved individually [7, 8]. In addition, such patients require the organisation of a multidisciplinary professional team (physicians, nurses, technicians, electricity providers, social workers, etc), able to work without interruption or default, particularly where patients are ventilated 24 hours a day, and we can learn much by trying to overcome such tough logistic challenges.

From a professional and human point of view, it has been a great privilege for me to share in the beginnings of home mechanical ventilation in my country, and I am convinced that to have taken care of such patients and their families has been of great help in the task of treating my present-day ICU patients.

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References

- 1 Kamm M, Burger R, Rimensberger P, Knoblauch A, Hammer J. Survey of children supported by long-term mechanical ventilation in Switzerland. *Swiss Med Weekly* 2001;131:261–6.
- 2 Fauroux B, Howard P, Muir JF. Home treatment for chronic respiratory insufficiency: the situation in Europe in 1992. The European Working Group on Home Treatment for Chronic Respiratory Insufficiency. *Eur Respir J* 1994;7:1721–6.
- 3 Jardine E, Wallis C. Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom. *Thorax* 1998;53:762–7.
- 4 Dhillon JS, Frewen TC, Singh NC, Speechley KN. Chronic mechanical ventilation-dependent children in Canada. *Paediatr Child Health* 1996;1:111–6.
- 5 Chevrolet JC, Fitting JW, Knoblauch A, Domenighetti G. Home mechanical ventilation in Switzerland in 1990. Future developments. *Schweiz Med Wochenschr* 1991;121:368–77.
- 6 Schweizerische Vereinigung gegen Tuberkulose und Lungenkrankheiten (SVTL) und Schweizerische Gesellschaft für Pneumologie (SGP). Richtlinien für die mechanische Heimbeatmung. *Schweiz Med Wochenschr* 1996;126:2191–6.
- 7 Hotes L, Johnson J, Sicilian L. Long-term care, rehabilitation and ethical considerations in the management of neuromuscular diseases with respiratory dysfunction. *Clinics in Chest Medicine*. 1994;15:783–95.
- 8 Polkey M, Lyall R, Craig Davidson A, Nigel Leigh P, Moxham J. Ethical and clinical issues in the use of home non-invasive mechanical ventilation for the palliation of breathlessness in motor neurone disease. *Thorax* 1999;54:367–71.

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