EDITORIAL

Oman Medical Journal [2019], Vol. 34, No. 5: 389-390

Home Ventilation for Children in Oman, Are We Prepared for this New Reality?

Hussain Mohsin

Department of Child Health, Royal Hospital, Muscat, Oman

ARTICLE INFO

Article history:

Received: 9 June 2019

Accepted: 4 August 2019

Online:

DOI 10.5001/omj.2019.72

Transitioning the complex care of children with different chronic disorders to their home environment has gained significant interest over the past three decades. The high cost of prolonged hospital stay, both financially and socially on families, necessitated this transition. Children who need long-term ventilation support, both invasively via tracheostomy or non-invasively (NIV), are a major group that requires such care. In fact, for many disorders such as congenital central hypoventilation syndrome, this is the standard of care rather than the exception.[1] The current evidence that these children have a better quality of life and development while being cared for at home supports this move towards home care.[2,3]

Studies from developed and developing countries demonstrated a significant increase in the number of children on long-term ventilation at home.[4–7] In Oman, there is currently no published data on the number of children on long-term ventilation at home. However, unpublished data from a single tertiary center (Royal Hospital, Muscat), revealed that since the first child was sent home on invasive ventilation in 2009, there has been an increase in this practice with 13 children currently followed on invasive ventilation.

Providing this care in Oman, like any other country, is surrounded by several ethical and practical challenges. Ethically, several questions need to be answered on a national level. First, who are the patients that will be supported at home? This decision is currently left to the treating team rather than based on specific clinical criteria, which could result in marked variability in patient care. The fear is that this option is given to inappropriate candidates who otherwise should receive palliative care and is not given to children who may have a meaningful benefit from home ventilation. Second, being in a culture where families rely on physicians to make passive decisions for them, how are we going to actively involve them in this major decision that will change their day-to-day life and social expectations? An example, to put this into perspective, is the change happening with what was considered a lethal neuromuscular disorder. Until recently, children with spinal muscular atrophy type 1 were managed palliatively in Oman like many parts of the world. However, with the recent advance in developing disease-modifying treatment,[8] there is a move towards active treatment. Manually assisted cough and secretion management is almost always needed to provide ventilation support (mostly NIV) for these children when an active treatment pathway is undertaken.[1] Such a decision has major implications on the health care systems and families. If we decided on a national level to move towards this practice then all aspects of the complex home care support for these children need to be addressed. Fragmented care will negatively impact the benefit of this expensive treatment. Soon, similar questions will come up for other disorders as well.

From a clinical perspective, the challenges are equally complex. These children and their families require organized teamwork to coordinate a safe home transition, which is often a lengthy process ranging from 46 days to 9.6 months for invasive ventilation.[9] Providing this level of care across the country (rather than only in Muscat), to ensure safety and health care equality, remains a challenge that requires specialized training. Also, depending on the complexity of child's condition, these children need a long list of equipment including ventilators, suction machines, and monitoring devices and although the cost of this equipment is relatively high, it is far less

*Corresponding author: ✉hussain.mohsin2@outlook.com

expensive than occupying an intensive care or high-dependency hospital bed.[10,11] Hence, since these children are provided free service in the hospital, it is logical to say that it is more cost-effective to provide funding for this home care.

Setting local standards of care that ensure safe, practical, and socially acceptable practice is another priority. These standards may deviate from those set internationally. For example, the standard of care published by the American[12] and Canadian[1] Thoracic Societies states that children with tracheostomy need to have 24-hour eyes on care by an awake adult. This is done practically by having caregivers, who are often not family members, stay in their homes overnight to observe the child. Applying this to our society would be challenging, both financially and socially. Alternatively, using pulse oximetry with an alarm has been used by practitioners in some areas of the world, but is not supported by enough evidence.[1] Whether we adopt this in our practice needs a careful assessment rather than personal decision because it concerns the major risk of accidental death. Other examples are beyond the scope of this article.

In the author's opinion, the following steps should be taken:

1. Establishment of dedicated multidisciplinary pediatric home ventilation teams at tertiary care centers in Oman, which includes members from intensive care, pulmonology, general pediatrics, nursing, social work, physiotherapy, speech and language therapy, respiratory therapy, and discharge planning teams. These teams should receive appropriate training in regard to pediatric home ventilation, followed by training assigned focal points at the secondary hospitals.

2. Assigning a task force to develop a national guideline that includes specific criteria of initiation of long-term ventilation and local standard of care to be applied across the country.

3. A national registry to capture all current and future patients.

4. The primary care department in different regions should take the lead in establishing home care nursing that does regular home visits for these children and provides needed support to the families.

In summary, long-term ventilation for children at home is a cost-effective practice that results in a better quality of life. This population is growing worldwide, and Oman cannot be an exception. However, learning from the experience of other countries, there are several key questions and challenges that require urgent attention on a national level to plan and organize this care before we end up with a more complex situation that is difficult to manage.

REFERENCES

1. Amin R, MacLusky I, Zielinski D, Adderley R, Carnevale F, Chiang J, et al. Pediatric home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline executive summary. Can J Respir Crit Care Sleep Med 2017;1(1):7-36.
2. González R, Bustinza A, Fernandez SN, García M, Rodriguez S, García-Teresa MÁ, et al; Spanish Children Home Mechanical Ventilation Multicentric Study Group. Quality of life in home-ventilated children and their families. Eur J Pediatr 2017 Oct;176(10):1307-1317.
3. Lumeng JC, Warschausky SA, Nelson VS, Augenstein K. The quality of life of ventilator-assisted children. Pediatr Rehabil 2001 Jan-Mar;4(1):21-27.
4. Oktem S, Ersu R, Uyan ZS, Cakir E, Karakoc F, Karadag B, et al. Home ventilation for children with chronic respiratory failure in Istanbul. Respiration 2008;76(1):76-81.
5. Amin R, Sayal P, Syed F, Chaves A, Moraes TJ, MacLusky I. Pediatric long-term home mechanical ventilation: twenty years of follow-up from one Canadian center. Pediatr Pulmonol 2014 Aug;49(8):816-824.
6. Bertrand P, Fehlmann E, Lizama M, Holmgren N, Silva M, Sánchez I. [Home ventilatory assistance in Chilean children: 12 years' experience]. Arch Bronconeumol 2006 Apr;42(4):165-170.
7. Edwards EA, Hsiao K, Nixon GM. Paediatric home ventilatory support: the Auckland experience. J Paediatr Child Health 2005 Dec;41(12):652-658.
8. Finkel RS, Mercuri E, Darras BT, Connolly AM, Kuntz NL, Kirschner J, et al; ENDEAR Study Group. Nusinersen versus sham control in infantile-onset spinal muscular atrophy. N Engl J Med 2017 Nov;377(18):1723-1732.
9. Amin R, Sayal A, Syed F, Daniels C, Hoffman A, Moraes TJ, et al. How long does it take to initiate a child on long-term invasive ventilation? Results from a Canadian pediatric home ventilation program. Can Respir J 2015 Mar-Apr;22(2):103-108.
10. Abbas Hassani S, Navaei S, Shirzadi R, Rafiemanesh H, Masiha F, Keivanfar M, et al. Cost-effectiveness of home mechanical ventilation in children living in a developing country 2019;51(1):35-40.
11. Edwards EA, Nixon GM; Australasian Paediatric Respiratory Group Working Party on Home Ventilation. Paediatric home ventilatory support: changing milieu, proactive solutions. J Paediatr Child Health 2013 Jan;49(1):13-18.
12. Sterni LM, Collaco JM, Baker CD, Carroll JL, Sharma GD, Brozek JL, et al; ATS Pediatric Chronic Home Ventilation Workgroup. An official American thoracic society clinical practice guideline: pediatric chronic home invasive ventilation. Am J Respir Crit Care Med 2016 Apr;193(8):e16-e35.