Domiciliary Management of Infants and Children with Chronic Respiratory Diseases

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There are number of reasons why the survival rate for premature infants, especially those born at < 28 weeks' gestation (extremely low birthweight or ELBW), has steadily improved [1-3] over the decades since newborn intensive care was introduced in the 1970's. These include improved obstetric practices such as administration of maternal antenatal corticosteroids, as well as multiple improvements in many aspects of neonatal care including gentler forms of mechanical ventilation and judicious use of supplemental oxygen [4-6]. Unfortunately, although survival has improved, the related morbidities such as severe intraventricular hemorrhage [7] or surgical necrotizing enterocolitis [8], and long-term complications such as bronchopulmonary dysplasia (BPD) have not improved as much. Regarding BPD, the rate has been stable at around 40% to 50% of ELBW survivors [9].

What has evolved is the recognition that long term hospitalization is not beneficial for the overall development of children. Newer technologies and increasing expertise in the paediatric respiratory community with home care for these complex patients has progressed over the last two decades [10]. Providing respiratory care in the home is increasingly being offered not just to former ELBWs with BPD or other related diseases of the newborn, but also to older children with complex disorders, including those with neuromuscular conditions [11], as well as, to children cared for in paediatric intensive care units (PICUs) who cannot easily be weaned from their respiratory support in a timely fashion [12].

Providing long term home respiratory care is complex. Factors that go into planning and executing such care include patient selection, equipment, financial considerations, family, and patient needs, desires, and fears, support systems, and communication among all the people involved.

As noted, this is a young medical field, and high-quality evidence for various components of home respiratory care for children remains rudimentary. Most reports are retrospective, mostly from single centers with few randomised trials. Nevertheless, the field is maturing quickly, as illustrated by the publication of guidelines from professional groups in Europe [13], Australia/New Zealand [14], Canada [15] and the US [16] about aspects of home respiratory care.

The two papers in this mini-symposium also reflect the development of the scientific literature about home-based respiratory care in children. MacLean and Faroux [17] outline the benefits and risk for long term home non-invasive ventilation and describe the current best practices to manage such children but point out wide variations observed even in resource rich countries. Fitzgerald [18] focuses on supplemental oxygen therapy at home, especially for former ELBWs who had BPD during their neonatal stay, for whom supplemental oxygen therapy had been a necessary evil during their first weeks of life. Both stress the importance of early and coordinated planning for discharge together with forming a partnership with the parents or guardians. Without the partnership with parents, given the extra burden placed on parents, adherence is likely to suffer. MacLean and Faroux [17] stress the variations for delivery of long-term ventilation between countries and even within countries. They also point out where improvements need to be made including in ensuring improved developmental and educational outcomes. Similarly, Fitzgerald [18] points out the severe lack of evidence to manage children, especially those recently discharged from the neonatal unit, for targeting optimal and safe oxygen saturation levels and, when the time comes, to optimally wean these infants and children from their supplemental oxygen. Both sets of authors identify the need for more coordinated action for international studies and guidelines to optimally manage their respective groups of discharged children.

Bringing together what is currently known about these two aspects of home respiratory care for children should increase that familiarity and expertise and give centers where this is not yet a practice much of the roadmap needed to start such a program. It is likely that over the next few years, as more children are cared for at home, more reports, including randomised trials, will necessitate an update. Stay tuned!

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