

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository:<https://orca.cardiff.ac.uk/id/eprint/161044/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Rozycki, Henry J. and Kotecha, Sailesh 2023. Domiciliary management of infants and children with chronic respiratory diseases. *Paediatric Respiratory Reviews* 47 , pp. 1-2. 10.1016/j.prrv.2023.04.001

Publishers page: <http://dx.doi.org/10.1016/j.prrv.2023.04.001>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Domiciliary Management of Infants and Children with Chronic Respiratory Diseases

¹Henry J Rozycki, ²Sailesh Kotecha

¹Children's Hospital of Richmond at VCU, Richmond, VA, USA

²Department of Child Health, Cardiff University School of Medicine, Cardiff, United Kingdom

Corresponding Author:

Professor Henry J Rozycki

Children's Hospital of Richmond at VCU

Box 980646

Richmond, VA USA 23298-0646

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!

References

1. Zayegh AM, Doyle LW, Boland RA, Mainzer R, Spittle AJ, Roberts G et al. Victorian Infant Collaborative Study Group. Trends in survival, perinatal morbidities and two-year neurodevelopmental outcomes in extremely low-birthweight infants over four decades. *Paediatr Perinat Epidemiol.* 2022 Sep;36(5):594-602. doi: 10.1111/ppe.12879.
2. Miyazawa T, Arahori H, Ohnishi S, Shoji H, Matsumoto A, Wada YS, et al. Mortality and morbidity of extremely low birth weight infants in Japan, 2015. *Pediatr Int.* 2023 Feb 5:e15493. doi: 10.1111/ped.15493.
3. Younge N, Goldstein RF, Bann CM, Hintz SR, Patel RM, Smith PB, et al. Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. Survival and Neurodevelopmental Outcomes among Periviable Infants. *N Engl J Med.* 2017 Feb 16;376(7):617-628. doi: 10.1056/NEJMoa1605566.
4. Quigley M, Embleton ND, McGuire W. Formula versus donor breast milk for feeding preterm or low birth weight infants. *Cochrane Database of Systematic Reviews* 2019, Issue 7. Art. No.: CD002971. DOI: 10.1002/14651858.CD002971.pub5
5. Martherus T., Oberthuer A., Dekker J., Hooper S.B., McGillick E.V., Kribs A., te Pas A.B. Supporting breathing of preterm infants at birth: A narrative review. *Arch. Dis. Child. Fetal Neonatal Ed.* 2019;104:F102–F107. doi: 10.1136/archdischild-2018-314898
6. Martin-Mons S, Lorrain S, Iacobelli S, Gouyon B, Gouyon JB; B-PEN Study Group. Antibiotics Prescription Over Three Years in a French Benchmarking Network of 23 Level 3 Neonatal Wards. *Front Pharmacol.* 2021 Jan 25;11:585018. doi: 10.3389/fphar.2020.585018.
7. Christian EA, Jin DL, Attenello F, Wen T, Cen S, Mack WJ, Krieger MD, McComb JG. Trends in hospitalization of preterm infants with intraventricular hemorrhage and hydrocephalus in the United States, 2000-2010. *J Neurosurg Pediatr.* 2016 Mar;17(3):260-9. doi: 10.3171/2015.7.PEDS15140.
8. Grisar-Granovsky S, Reichman B, Lerner-Geva L, Boyko V, Hammerman C, Samueloff A, Schimmel MS;

- Israel Neonatal Network. Population-based trends in mortality and neonatal morbidities among singleton, very preterm, very low birth weight infants over 16 years. *Early Hum Dev.* 2014 Dec;90(12):821-7. doi: 10.1016/j.earlhumdev.2014.08.009
9. Horbar JD, Edwards EM, Greenberg LT, Morrow KA, Soll RF, Buus-Frank ME, Buzas JS. Variation in Performance of Neonatal Intensive Care Units in the United States. *JAMA Pediatr.* 2017 Mar 6;171(3):e164396. doi: 10.1001/jamapediatrics.2016.4396. Erratum in: *JAMA Pediatr.* 2017 Mar 1;171(3):306.
 10. McDougall CM, Adderley RJ, Wensley DF, Seear MD. Long-term ventilation in children: longitudinal trends and outcomes. *Arch Dis Child.* 2013 Sep;98(9):660-5. doi: 10.1136/archdischild-2012-303062.
 11. Fauroux B, Khirani S, Griffon L, Teng T, Lanzeray A, Amaddeo A. Non-invasive Ventilation in Children With Neuromuscular Disease. *Front Pediatr.* 2020 Nov 16;8:482. doi: 10.3389/fped.2020.00482.
 12. Yagiela LM, Barbaro RP, Quasney MW, Pfarr MA, Ursu DC, Prosser LA, Odetola FO. Outcomes and Patterns of Healthcare Utilization After Hospitalization for Pediatric Critical Illness Due to Respiratory Failure. *Pediatr Crit Care Med.* 2019 Feb;20(2):120-127. doi: 10.1097/PCC.0000000000001797. PMID: 30418338.
 13. Fauroux B, Abel F, Amaddeo A, Bignamini E, Chan E, Corel L. et al. ERS statement on paediatric long-term noninvasive respiratory support. *Eur Respir J.* 2022 Jun 2;59(6):2101404. doi: 10.1183/13993003.01404-2021.
 14. Chawla J, Edwards EA, Griffiths AL, Nixon GM, Suresh S, Twiss J, et al. Ventilatory support at home for children: A joint position paper from the Thoracic Society of Australia and New Zealand/Australasian Sleep Association. *Respirology.* 2021 Oct;26(10):920-937. doi: 10.1111/resp.14121. Epub 2021 Aug 13.
 15. 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, *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine* 2017, 1:1, 7-36, DOI: 10.1080/24745332.2017.1300463

16. Sterni LM, Collaco JM, Baker CD, Carroll JL, Sharma GD, Brozek JL, et al. An Official American Thoracic Society Clinical Practice Guideline: Pediatric Chronic Home Invasive Ventilation. *Am J Respir Crit Care Med*. 2016 Apr 15;193(8):e16-35. doi: 10.1164/rccm.201602-0276ST
17. Maclean JE, Fauroux B. Long-term non-invasive ventilation in children: transition from hospital to home. *Paediatric Respiratory Reviews*. 2023 Jan 12.
18. Fitzgerald DA. The infant with bronchopulmonary dysplasia on home oxygen: The oxygen weaning conundrum in the absence of good evidence. *Paediatric Respiratory Reviews*. 2023 Jan 25.