



COMMENT

Ensuring the care for our youngest graduates with medically complex conditions

Scott A. Rivkees^{1,2} and Valerie Opiari^{1,2} On behalf of the Pediatric Policy Council

Pediatric Research (2019) 85:253–254; <https://doi.org/10.1038/s41390-018-0233-3>

Children with medical complexity account for up to 5% of the pediatric population and about 60% of pediatric healthcare costs.^{1–3} This population of children requires special services, many of which can only be found at specialized children's hospitals or general hospitals with robust pediatric programs. A sizable proportion of children with medically complex conditions are graduates of neonatal intensive care units.^{4–6} In this issue of *Pediatric Research*, three reports detail outcomes of interventions in the neonatal intensive care unit, whose graduates may need special services after their discharge to home.^{6,7}

The report by Ballard et al.⁸ focuses on concentrations of intra-alveolar surfactant and its relationship to the development of the chronic condition bronchopulmonary dysplasia. Vernon et al.⁹ address the application of forced oscillation and effects on the development of bronchopulmonary dysplasia. Ruys et al.¹⁰ focus on relationships between growth patterns of premature infants and neurodevelopmental outcome. Each of these reports represents an important contribution to the care of premature infants. Yet, each of these reports recognizes the fact that graduates of neonatal intensive care units may be left with chronic conditions that will require specialized attention and in many instances lifelong medical support.

Taking care of children with medically complex conditions often requires the input of different specialties and advanced therapies. In fact, children with medical complexity see about 13 outpatient physicians per year from up to six distinct medical specialties.^{5,11} When it comes to inpatient hospital care, children with medical complexity can account for up to 13% of pediatric hospitalizations and account for 47% of inpatient hospital service requirements.⁴ As such, this special group of children requires focused attention and coordinated care for both outpatient and inpatient activities.^{4,12}

Important data as to how best to care for these children comes from the Children's Hospital Association's \$23 million Health Care Innovation Award from the Center for Medicare and Medicaid Innovation (CMMI), focusing on coordinating and improving care for these children and their families enrolled in Medicaid.⁹ By developing patient-centered medical homes for children with medical complexity,¹² the participating study sites were able to demonstrate a 40% reduction in hospitalizations, a 10% reduction in emergency room utilization, and nearly a 7% reduction in healthcare expenditures.⁹ This program involved the development of multidisciplinary clinics and the direct involvement of physicians with expertise in complex care.

The benefit of specialized inpatient clinical services focusing on children with medically complex conditions has also been demonstrated at several institutions.⁴ Such programs focus on

enhancing communication and care among specialists, primary care physicians, home care agencies, educational institutions, and primary caregivers to support the medical and developmental needs of children in their communities. We also need to be creative and flexible in providing healthcare to children with medically complex conditions who may not live in close proximity to specialized services. As such, telemedicine models, such as Project ECHO, can be considered as potential solutions for addressing the care of these children with respect to specialty care at a distance.¹³

It is important to note that both outpatient and inpatient programs for medically complex children require financial support.⁷ However, whereas it is financially advantageous to provide neonatal intensive care unit care, the post discharge care of infants needing extra attention is a financial liability.⁷ As such, institutions caring for preterm infants need to develop fund flow mechanisms to support the continued care of neonatal intensive care unit graduates.

Regional health plans with expertise in the care of children with medically complex conditions also have proven efficacy.¹⁴ Because the cost of care for children with medically complex conditions is expensive, efforts have been undertaken at the federal and state levels to provide for the care of these children in capitated insurance programs.¹⁵ To date, the efficacy of such capitated programs has not been fully evaluated and vetted, and some states have found the traditional fee-for-service model to be preferred.¹⁵ An increasing challenge of capitated systems will be covering the costs of novel treatments for children with medically complex conditions, some of which can reach \$750,000 per year.¹⁶ The coverage of this medication is now being mandated by some state Medicaid programs.¹⁰ Without outlier cost exception coverage provided by funding agencies, payment of these hefty costs has the potential to result in the reduction in services for other children under capitated programs. Unfortunately, mechanisms are not universally in place to help with this problem.

The care of children with complex medical conditions may also require the expertise of programs and practitioners that are not available locally.¹⁷ Thus, the opportunity for distant care of these children is needed. It is important to note that the support for pediatric specialty programs varies from state to state, along with local capabilities.¹⁷ As such, some children with medically complex conditions may need to travel out of state to obtain necessary care. This issue is a major problem for a number of rural areas, states, and entire sections of this country without pediatric tertiary care centers.

To provide financial support for the care of these children, it is gratifying that the Children's Health Insurance Program (CHIP) was

¹Department of Pediatrics, University of Florida, Gainesville, FL, USA and ²Department of Pediatrics, University of Michigan, Ann Arbor, MI, USA
Members of the Pediatric Policy Council are listed at the end of the paper.

renewed more than a year ago until 2023.¹⁸ Yet, it is unfortunate and cruel that there have been recent political overtures to reduce CHIP funding.¹⁹ As such, continued advocacy efforts are needed for CHIP preservation. It is also important to recognize that children with chronic conditions continue to have access to affordable health insurance, as efforts are underway in some areas that may impact health care coverage for individuals with pre-existing conditions.^{20,21}

It is most laudable that legislative efforts are underway to help augment the care of children with medically complex conditions through the Advancing Care for Exceptional Kids Act (ACE Kids Act; S.428, H.R. 3325).^{22,23} A foundation of this act is to develop patient-centered medical homes for children with medically complex conditions, support programs that can deliver advanced pediatric specialty services, and allow children to obtain out-of-state care when needed. It is also projected that this act could potentially save more than \$10 billion in healthcare costs over its first 10 years.²³

As the inpatient care of premature babies continues to march forward with incredible progress, as reflected in the important reports in this issue of *Pediatric Research*,^{8–10} we need to recognize that a proportion of neonatal nursery graduates will need specialized services over the years of development and learning ahead. It remains our obligation to be sure that our view of neonatology and neonatal services follows those children and their families after they have left the practitioner and service-rich confines of the hospital, and that continued research efforts are also needed to focus on improvement of their health and quality of life.

ADDITIONAL INFORMATION

Competing interests: The authors declare no competing interests.

Publisher's note: Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

REFERENCES

1. Childrens Hospital Association. *About the CARE Award*. <https://www.childrenshospitals.org/Care/About-CARE-Award>. Accessed 8 Oct 2018.
2. Berry, J. G. et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff. (Millwood)* **33**, 2199–2206 (2014).
3. Murphy, N. A. & Clark, E. B. Children with complex medical conditions: an under-recognized driver of the pediatric cost crisis. *Curr. Treat. Options Pediatr* **2**, 289–295 (2016).
4. Berry, J. G. et al. Characteristics of hospitalizations for patients who use a structured clinical care program for children with medical complexity. *J. Pediatr.* **159**, 284–290 (2011).
5. Cohen, E. et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics* **127**, 529–538 (2011).
6. Schell, S. et al. Maturational, comorbid, maternal and discharge domain impact on preterm rehospitalizations: a comparison of planned and unplanned rehospitalizations. *J. Perinatol.* **36**, 317–324 (2016).
7. Lantos, J. Cruel calculus: why saving premature babies is better business than helping them thrive. *Health Aff. (Millwood)* **29**, 2114–2117 (2010).
8. Ballard, P. L. et al., TOLSUR Investigators. Surfactant status and respiratory outcome in premature infants receiving late surfactant treatment. *Pediatr. Res.* in press (2019).
9. Veneron, C., Wallström, L., Sindelar, R. & Dellaca, R. L. Oscillatory respiratory mechanics on the first day of life improves prediction of respiratory outcomes in extremely preterm newborns. *Pediatr. Res.* in press (2019).
10. Ruys, C. A., et al. Early-life growth of preterm infants and its impact on neurodevelopment. *Pediatr. Res.* in press (2019).
11. Cohen, E. et al. Patterns and costs of health care use of children with medical complexity. *Pediatrics* **130**, e1463–e1470 (2012).
12. Palfrey, J. S., Pediatric Alliance for Coordinated C. et al. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. *Pediatrics* **113**, 1507–1516 (2004).
13. Rapoport, B. Pathophysiology of Hashimoto's thyroiditis and hypothyroidism. *Annu. Rev. Med.* **42**, 91–96 (1991).
14. Giunta, N., Philip, C., Saliba, H., Rivkees, S. A. & Nackashi, J. The State of Florida, University-Based Pediatric Integrated Care System (Ped-I-Care) for Children with Special Health Care Needs. *J. Pediatr.* **170**, 5–6 e1 (2016).
15. Baylit Helath. *Report to the Schuyler Center for Analysis and Advocacy and the United Hospital Fund. Value-Based Payment Models for Medicaid Child Health Services* (2016).
16. Kaiser Helath News. *Drug Puts A \$750,000 'Price Tag On Life.'* <https://khn.org/news/drug-puts-a-750000-price-tag-on-life/> (2018).
17. EPSDT. *A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf (2018).
18. Kaiser Helath News. *Summary of the 2018 CHIP Funding Extension*. <https://www.kff.org/medicaid/fact-sheet/summary-of-the-2018-chip-funding-extension/> (2018).
19. Kaiser Health. *4 Takeaways From Trump's Plan To Rescind CHIP Funding*. <https://khn.org/news/4-takeaways-from-trumps-plan-to-rescind-chip-funding/> (2018).
20. Reinehr, T., de Sousa, G. & Andler, W. Hyperthyrotropinemia in obese children is reversible after weight loss and is not related to lipids. *J. Clin. Endocrinol. Metab.* **91**, 3088–3091 (2006).
21. Lafranchi, S. Thyroiditis and acquired hypothyroidism. *Pediatr. Ann.* **21**, 32–29 (1992).
22. S.428—ACE Kids Act of 2017. <https://www.congress.gov/bill/115th-congress/senate-bill/428> (2018).
23. ACE Kids Act. https://www.speaknowforkids.org/ace_kids_act (2018).