

Guest Editorial

Complex Care in Pediatrics: Great Progress, Greater Challenges

Rishi Agrawal

Ann & Robert H. Lurie Children's Hospital of Chicago, La Rabida Children's Hospital, 225 E. Chicago Ave. #152, Chicago, IL 60611, USA

Tel.: +1 312 227 4000; Fax: +1 773-363-1488; E-mail: ragrawal@luriechildrens.org

Abstract. There has been tremendous recent growth in the field of pediatric complex care. Complex care programs are attracting the attention of policy makers at the national level. Key challenges for the field include development of a consensus method to identify children with medical complexity, promotion of high quality research, navigation of health care reform, and measures to promote professional identity and workforce development.

Keywords: Children with medical complexity, children with special needs, health care reform

1. Introduction

This month, the *Journal of Pediatric Rehabilitation Medicine* devotes an issue to Complex Care, a growing area within pediatrics and rehabilitation medicine. Children with Medical Complexity (CMC) are conceptualized as having severe chronic conditions, substantial functional limitations, high level of family needs, and increased resource utilization [1]. A common example is a child with spastic quadriplegia, seizure disorder, gastrostomy feedings, and tracheostomy for airway maintenance who requires multiple providers and struggles with getting services in a fragmented health care system. Others may have genetic conditions which affect multiple organ systems. Some acquire their complex conditions after surviving prematurity, birth asphyxia, central nervous system infections, child abuse, or motor vehicle collisions.

While advances in pediatric specialty care have fueled the growth of this patient population, there has been little interest in delivering comprehensive care coordination to these children until recently. A number of providers of complex care began collaborating in 2008, leading to the formation of a special interest group within the Academic Pediatric Association in 2009 and

in the American Academy of Cerebral Palsy and Developmental Medicine in 2011. The combined listserv membership of these groups now exceeds 700. There has been tremendous growth in complex care clinical programs that have caught the attention of policy makers on a national level because of their promise to improve care and reduce spending. The federal Center for Medicare and Medicaid Innovation has recognized children with medical complexity as a priority population for Innovation Awards. The Children's Hospital Association is actively promoting legislation designed to improve care for children with medical complexity in Congress [2]. Rapid increases in the amount of scholarly activity devoted to this patient population are in progress, including presentations at national meetings and peer-reviewed publications. For the first time, there was a platform session devoted to Children with Medical Complexity at the Pediatric Academic Societies meeting in 2015.

It is in this context of rapid growth that we are very pleased to devote an issue of the *Journal of Pediatric Rehabilitation Medicine* to complex care. This issue presents a range of original research on children with medical complexity, with important areas of investigation including quality of life, caregiver challenges,

health care utilization, technology assistance and residency education. These excellent pieces of research help advance our understanding of the needs of these children.

While great progress has been made in the last few years in terms of elevating the academic, clinical, and policy visibility of such children and their providers, the field of complex care still has many challenges to confront if it is to succeed in its objective of maximizing quality of life and developmental outcomes for as many children as possible.

2. Identifying children with medical complexity

The medical complexity of a given child can seem obvious when presenting clinically. However, there is a cacophony of approaches to identifying such children on a health system or population health level. Systems have been developed using ICD-9 codes, such as Feudtner's Complex Chronic Conditions [3] and 3M's Clinical Risk Groups [4] to identify children with medical complexity based on their coded conditions. Researchers have used combinations of responses from the National Survey of Children with Special Health Care Needs to identify subgroups of CMC. Complex clinical programs based in tertiary care centers usually use a variety of homegrown parameters to identify children for enrollment: number of specialists, repeated hospitalization, assistance with medical technologies, etc.

To some extent, the divergent approaches to identification of CMC may reflect the different priorities of various stakeholders. Academic researchers have an interest in a definition that is standardized, validated, and reproducible across settings. Complex care program directors may have an interest in definitional specificity over sensitivity, prioritizing those children most in need of their limited programmatic resources over others whose needs are being met by existing care arrangements among primary care physicians and subspecialists. In contrast, children's hospitals may have an interest in a definition that is more sensitive than specific in order to improve the payment and financing mechanisms for as many children as possible. These divergences were starkly presented during the launch of a recent child themed issue of *Health Affairs*, in which one article posited a prevalence of CMC of 0.4–0.7% [5], while an accompanying blog post by the CEO of the Children's Hospital Association posited the prevalence to be an order of magnitude higher: 6% of all children [6].

In truth, medical complexity is likely a spectrum, not a dichotomous variable. The heterogeneity of conditions, variable fragility of health of those with these conditions, and different needs of families for care coordination and other supports makes it likely that all of our existing systems of identification are gross oversimplifications of a dynamic state that is, well, complex.

In order to provide more coherence to our discussion of these children, we must strive to avoid conflation of various groups of children: children with special health care needs, children with severe chronic conditions, children who are high utilizers of health care resources, and those children who can benefit from a dedicated complex care program. While there is much overlap and similarity among these groups, they are neither identical nor interchangeable with "children with medical complexity," a conceptual designation that lacks a precise definition at this time. It should be a priority for the field to develop a consensus system for identifying and perhaps stratifying children with medical complexity.

3. Research on caring for children with medical complexity

There is a growing body of research examining the health services utilization of children with medical complexity, who typically are responsible for a disproportionate share of health care resources. Studies examining the impact of complex care programs on health outcomes and utilization are increasing as well. Investigators are also examining quality of life, caregiver challenges, training needs, and other topics related to children with medical complexity. These efforts need to be encouraged, and given the disproportionate impact of this small group of patients on the pediatric health care system, there is ample justification for increased funding for such investigation from both private and governmental sources.

One area of research faces particular challenges. Clinicians who care for children with medical complexity in the clinical setting are severely limited by the lack of published clinical research to provide an evidence base for many care practices. How should one manage pneumonia in CMC? What are the most effective regimens of airway clearance in children with complex respiratory problems? How do clinicians most effectively choose schedules for enteral nutrition? When reflux and aspiration are a concern, when should

Nissen fundoplication be chosen over gastrojejunostomy? How is chronic pain of visceral or neuropathic etiology best managed? Such questions are often posed on the complex care listserv, and the typical diversity of responses shows how much of individual clinician decision-making lacks clear evidence, and is instead driven by prevailing customs of clinical practice. It is critical to find ways to increase the amount of clinical research in pediatric complex care to build a stronger base of evidence on which to make care decisions. Given that many of these clinical problems cross traditional subspecialty boundaries, it is likely that interdisciplinary research teams will be needed to complement interdisciplinary clinical teams.

4. Navigating health care reform

Health care reform at the state and federal level poses both opportunities and perils in the years ahead for children with medical complexity. The development of health insurance marketplaces ensures that middle income families have a source of insurance even if not provided by an employer. However, weak implementation of the essential health benefit standard of benefits for such plans gives health plans latitude to deny coverage for many services required by children with medical complexity. Marketplace plans often have restrictive provider networks that may not include children's hospitals, limiting the selection of qualified providers for children with medical complexity.

In Medicaid, health care reform mandates that states maintain current level of eligibility for Medicaid through 2019. The Children's Health Insurance Program was recently re-authorized through 2017. There is uncertainty about the long-term future for children in Medicaid expansions or CHIP, and whether states will have incentive to move them to Marketplaces in the future with less access to services needed by CMC.

Low reimbursement remains a challenge for the care of CMC in Medicaid. While Medicaid primary care payments were increased temporarily in 2013 and 2014 to Medicare levels, funding to continue this increase has yet to be extended. States receive a lower percentage of funding from the federal government to provide services to children with medical complexity than adults newly enrolled in the program, and thus they have incentive to limit reimbursement for such services. For example, Illinois attempted to make severe cuts to its home and community based waiver program for children with technology assistance, but re-

versed course after legal action by the families of children affected. While there are anecdotal reports of cuts to home care services throughout the country, there is no systematic way of tracking these issues, which tend to receive far less attention than those of provider and hospital reimbursement, but are of key importance to families.

The movement to electronic health records promoted by health reform has important implications for the practice of complex care coordination, which is, in part, an exercise in information management. However, the limitations of such software systems in creation and maintenance of longitudinal care plans and summaries are a missed opportunity. The lack of interoperability and availability of robust health information exchanges means that data in electronic health records remain in siloes, which is particularly problematic for children with medical complexity who receive care from multiple providers across the continuum of care. Telemedicine has the potential to greatly improve care for CMC and perhaps prevent unnecessary utilization, but is limited by inadequate reimbursement in many locales.

Health reform incentivizes a move from fee-for-service payment to risk-based payment structures. Various states are experimenting with such models and the federal Center for Medicare and Medicaid Innovation has funded a number of complex care projects that aim to save money though enhanced care coordination. The Children's Hospital Association has legislation in Congress that creates an option to move children with severe chronic conditions and medical complexity out of traditional Medicaid into a national network of providers anchored in Children's Hospitals. The potential benefits to such changes include enhanced financial support for care coordination and complex care programs, as well as options for children to receive care across state lines. Potential perils include provider networks that restrict patient choice and the potential for harm in prioritizing short-term financial savings over long-term goals.

Those clinicians who care for children with medical complexity should retain a healthy skepticism of all the attention such children are receiving as potential sources of saved financial resources. While some patients, perhaps the most fragile, are likely to have preventable health care utilization, other CMC may have unmet needs for home care, habilitative therapies, durable medical equipment, transportation, mental health care, and other services. In some locations, spending on such children has been falling even in a fee-for-service environment [7].

Whether there is enough savings in Medicaid – a program historically plagued by low reimbursement – from preventable utilization to meet the unmet needs of these children remains to be seen. Specifically, it is not yet clear whether savings achieved in small groups of the most fragile and complex children can be extrapolated to broader, less severe cohorts of children with similar conditions. As these changes go forward, the pressure to save resources must be balanced by attention to the rights of children with disabilities to receive those services needed to maximize their developmental outcomes and family functioning. Ideally, these goals will be synergistic, but it will take vigilance and advocacy to ensure that this is the case.

5. Development of a workforce and a professional identity

Complex care is a growth area, and there will be a need for qualified providers from different disciplines to staff complex care programs in the future. The interdisciplinary nature of complex care is a strength in terms of providing effective, family centered care, but may be a barrier in terms of creating a professional identity and specific measures to promote workforce development. What sort of training is required to provide complex care? What competencies are necessary to deliver such care? How do we encourage trainees to pursue a career in this area? Should the field evolve into a subspecialty or remain an advanced form of generalist medicine? Is there a need for a professional organization to create an infrastructure to catalyze

advancement in the field, or should progress continue in an organic fashion? There is a range of valid perspectives on these questions among complex care clinicians. In order to improve the experience of care for as many CMC as possible, these issues must be addressed more formally in the coming years.

References

- [1] E. Cohen, D.Z. Kuo, R. Agrawal et al., Children with medical complexity: An emerging population for clinical and research initiatives, *Pediatrics* **127**(3) (2011), 529–538.
- [2] V. Dickson, Bipartisan bills would let severely ill Medicaid kids get out-of-state care. [Internet], Chicago: Modern Healthcare; Feb 3 2015 [cited 2015 Apr 21]. Available from: <http://www.modernhealthcare.com/article/20150203/NEWS/302039948/>.
- [3] C. Feudtner, D.A. Christakis and F.A. Connell, Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980–1997, *Pediatrics* **106**(1 pt 2) (2000), 205–209.
- [4] J.M. Neff, V.L. Sharp, J. Muldoon, J. Graham and K. Myers, Profile of medical charges for children by health status group and severity level in a Washington State Health Plan, *Health Serv Res* **39**(1) (2004), 73–89.
- [5] J.G. Berry, M. Hall, J. Neff, D. Goodman, E. Cohen, R. Agrawal, D. Kuo and C. Feudtner, Children with medical complexity and Medicaid: spending and cost savings, *Health Aff (Millwood)* **33**(12) (2014), 2199–206. doi: 10.1377/hlthaff.2014.0828.
- [6] M. Wietecha, Evolving Medicaid to better serve children with medically complex conditions. [Internet]. Bethesda: Health Affairs Blog; Dec 8 2014 [cited 2015 Apr 21]. Available from: <http://healthaffairs.org/blog/2014/12/08/evolving-medicaid-to-better-serve-children-with-medically-complex-conditions/>.
- [7] R. Agrawal, T. Smith, Y. Li and J. Cartland, Rate of spending on chronic conditions among Medicaid and CHIP recipients, *Pediatrics* **134**(1) (2014), e80–e87.