Three million children in the United States have medical conditions that can be expected to last at least one year (unless death intervenes), and to require specialty pediatric care and a period of hospitalization in a tertiary, or specialty care center.\(^1,2\)

Though the number of children with medical complexity (CMC) is relatively small, CMC make up 6 percent of the 35.5 million children on Medicaid or CHIP.\(^3\) In other words, two million of the total three million children with medical complexity are insured through either Medicaid or CHIP.\(^4\) The number of CMC covered by Medicaid or CHIP is expected to double by 2024.\(^5\)

Although health care spending for CMC is relatively high, the long-term health outcomes for CMC are serious, often requiring a hospital stay of longer than a week or an ICU admission, or even resulting in death. Their day-to-day care is intensive, and may include ventilator assistance or use of a feeding tube.\(^6\) Because there is a relatively small CMC population, such children are often overlooked in the policymaking process despite their significant cost burden on the American health care system. Thus, developing health care policies to meet their needs is both imperative and productive for CMC and the U.S. population as a whole.

CMC have extensive and costly service needs due to their severe chronic conditions, such as muscular dystrophy or cystic fibrosis, and their associated functional limitations.\(^7\) As a result, CMC depend on technology and multiple providers for acute and daily needs, and their families must often provide home care equivalent to that of a hospital. Many family members experience significant financial costs because caring for CMC requires out-of-pocket expenses, and caregivers have to miss work or eventually leave work altogether.\(^8\) This often results in CMC’s dependence on financial assistance such as Medicaid for health coverage and a need for streamlined and accessible care.

Coordination is essential to providing CMC with efficient and effective care. Efforts are underway to move CMC care toward the patient-centered medical home model in which their primary care physician coordinates their treatment and care delivery. Patient-centered medical homes (PCMH) are patient-driven, team-based, and outcomes-focused. They take a holistic and comprehensive approach to care for CMC, emphasizing health promotion and thorough care.\(^9\) The shift to PCMH could save Medicaid anywhere from $6 billion to $26 billion in

Though the number of children with medical complexity (CMC) is relatively small, CMC make up 6 percent of the 35.5 million children on Medicaid or CHIP.
The shift to patient-centered medical homes (PCMH) could save Medicaid anywhere from $6 billion to $26 billion in spending over 10 years but would also require a shift toward telemedicine for the optimal efficacy and efficiency of this model of care so that children with medical complexity do not have to physically go to their PCMH for every day-to-day need.

spending over 10 years but would also require a shift toward telemedicine for the optimal efficacy and efficiency of this model of care coordination, allowing CMC to not have to physically go to their PCMH for every day-to-day need. CMC’s significant chronic and acute medical needs would benefit from this innovative care approach because it would allow families to avoid an expensive and often inconvenient hospital visit, which is a notable benefit to families and the health care system.

In 2014, The University of Texas at Houston did a cost analysis of treating high-risk children. High-risk children were defined as those with chronic illnesses and at least three emergency department visits, two hospitalizations, or one pediatric intensive care unit admission over the previous year. CMC often fall into this high-risk designation, making this study a pertinent effort to review regarding how to best coordinate their care. Comprehensive care fits within the medical home model, in which the child receives treatment from primary care clinicians and specialists in one location. The study compared this comprehensive care model (which entailed a medical home with a medical director, two pediatric nurse practitioners, a nutritionist, a social worker, and regular visits from specialists) to the traditional care model (in which children were treated without a comprehensive care model at a high-risk clinic or in private offices elsewhere). The main finding was that the comprehensive care model yielded more efficient and effective care across the board. Comprehensive care was shown to decrease total clinic costs by more than $10,000 per child and reduce Medicaid payments by over $6,000 per child.

The medical home or comprehensive care model is a positive shift to optimize quality and reduce cost of care for CMC. A barrier to its implementation is the growing shortage of primary care physicians, predicted to be between 46,000 and 90,000 by 2025. This shortage is particularly problematic in rural areas. Roughly 20 percent of Americans live in rural areas, but only 10 percent of U.S. physicians work in rural areas. As such, it is likely that some CMC may have to travel significant distances to reach their medical home.

Telemedicine, defined as “the use of health care information exchanged from one site to another via electronic communications for the health and education of the individual or provider and for the purpose of improving patient care, treatment, and services,” is a potential solution to increasing access to the aforementioned medical homes, particularly in rural areas. Telemedicine has two crucial components that could benefit CMC and improve their care.

Telemedicine allows remote diagnosis and treatment of patients via telecommunications. Its utility in the sharing of medical information would allow CMC to receive referrals and subspecialty care at their patient-centered medical home, otherwise known as their primary doctor’s office, regardless of its proximity to their house. This would also allow CMC to maintain a stronger overall connection with their principal care team. Telemedicine models could and likely will vary from county to county or state to state, but encouragement at the federal level for care coordination and improved access through the use of telemedicine could help to lower costs and provide better quality medical services.

However, like the medical home model itself, telemedicine also has obstacles to its implementation. These include the costs of purchasing and implementing the necessary technology, the determination of which consultations warrant in-person visits, and the impact on the caregiver. Responses to a survey by the American Academy of Pediatrics revealed much confusion about the federal Health Insurance Portability and Accountability Act’s (HIPAA) stance on telemedicine. This makes patients uncomfortable using the service, and doctors are unsure of how to explain telemedicine to their patients while also ensuring that their private information is being properly protected. Additionally, many CMC and their families are reluctant
to see their primary care physician, reporting that these clinicians generally do not “take the time to understand and take charge of their child’s health problems, help CMC when they are facing urgent health problems, or sufficiently coordinate care with the children’s specialty physicians and therapists.”16 Although telemedicine could increase accessibility to primary care services, CMC and their families still may not want to rely on them. Finally, telemedicine has been proven to be most useful when used in a medical home with access to an integrated electronic medical records system and numerous subspecialists.17 This allows telemedicine to supplement the medical home model and improve care coordination. However, the lack of this technology or infrastructure has the potential to make incorporating telemedicine into care for CMC difficult.

Children with medical complexity make up a small portion of children in the United States, but they pose a significant cost burden to the American health care system and to their families as high utilizers of health services. By coordinating care and increasing the ease of access to health care through the use of telemedicine, there is the potential to improve the quality of care for CMC and decrease unnecessary costs of care.

ENDNOTES


5. Book and Holtz-Eakin, “Prospects for Care Coordination for Children with Medical Complexity.”


The medical home or comprehensive care model is a positive shift to optimize quality and reduce cost of care for CMC.
17. Deshpande and Burke, “Telemedicine a vital tool for patient-centered medical home.”

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