

# Polypharmacy—An Important Contributor to Health and Safety for Children With Medical Complexity: How Can We Improve Care for This Vulnerable Population?

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**ABBREVIATIONS** CMC, children with medical complexity; EES, erythromycin ethylsuccinate; GJ, gastrojejunostomy; PLTC, pediatric long-term care

**KEYWORDS** children with medical complexity; pediatric complex care; pediatric long-term care; pharmacist; polypharmacy

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Children with medical complexity (CMC) pose unique challenges to the health care system because of their substantial health care needs and unmet needs for care coordination across the continuum of care from the hospital to home. Polypharmacy is an underrecognized contributing factor to maintain the health and safety of these patients. In this issue, Quinn et al<sup>1</sup> highlight the importance of a collaborative medical management program in the pediatric long-term care (PLTC) setting to improve safety and health care, reduce adverse events, and reduce costs, all of which are aligned with the Triple Aim endorsed by most health care systems, payors, and policymakers. This unique study<sup>1</sup> examines the role of the pharmacist in the PLTC setting, whereas similar studies have focused exclusively on the outpatient or acute care setting.<sup>2,3</sup> The cornerstone of their intervention, regardless of where the child lives, is the unique dyadic relationship between an experienced health care provider and pharmacist. Sadly, the availability of such health care providers is limited, particularly in environments outside of major academic medical centers. Innovative strategies have focused on care team structure and function and establishing best practices to treat their multiple medical complexities. However, polypharmacy, often a significant contributor to health and safety, is often overlooked. In order to be effective, however, strategies to improve the care of CMC must be implemented in all care environments where CMC live and should include pharmacy support, despite the challenges brought about by workforce shortages and/or clinical knowledge gaps.

## Characteristics of CMC

Children with medical complexity have multiple system involvement, substantial health care use, and significant limitations to function. Although CMC comprise less than 1% of all US children, they account for an

estimated 30% of all pediatric health care costs,<sup>4</sup> 56% of pediatric hospital admissions, 82% of hospital days, and 86% of hospital charges.<sup>5</sup> Admissions for CMC continue to rise, placing a burden on pediatric hospitals with diminishing resources to effectively manage their care.<sup>6</sup>

Most CMC live at home, with significant care demands often taking a significant emotional toll on parents and siblings. Estimates of CMC generally assume a prevalence of 0.5%, or approximately 400,000 of all US children.<sup>7</sup> In 2000, the Centers for Medicare & Medicaid Services reported that there were 4886 children with special health care needs in the United States residing in skilled nursing facilities, of whom 1222 had intellectual and developmental disabilities.<sup>8</sup> This number may not account for children living in intermediate care facilities, acute care or specialty hospitals, transitional facilities, residential schools, medical group homes, or rehabilitation hospitals. Whether at home or in a facility, however, care coordination programs must address needs of CMC in both the inpatient environment and the community.

## Pediatric Complex Care Programs

Patient-centered medical homes, in home care, telehealth, and disease-specific specialty clinics, have been implemented, with the goal of increasing health care value for CMC. Pediatric complex care programs within academic children's hospitals, although varied by team composition and patient scope, provide care coordination in the inpatient, outpatient, and long-term care environment. These teams generally are composed of physicians with general or subspecialty training, nurse practitioners, nurse coordinators, social workers, and dietitians. Although some inpatient programs include pharmacists, most outpatient programs do not. The inclusion of pharmacists on inpatient care teams for children with CMC has demonstrated significant

reductions in medication error and adverse events and has led to improved outcomes and decreased length of stay.<sup>2,3</sup> Quinn et al<sup>1</sup> also demonstrated the benefit of medication management in PLTC, as evidenced by 13 interventions per patient when drug therapy problems were identified, an overall reduction in number of average medications administered from 23 to 20 per patient, and avoidance of costly adverse events that were likely to require hospitalization.

Workforce shortages and lack of experience and knowledge due to poor educational and training opportunities related to CMC have made finding qualified candidates to join complex care teams challenging. Despite these challenges, pediatric complex care programs would greatly benefit from pharmacist support to meet the pharmacologic management needs of CMC patients across all environments of care.

## A Case Study

Stephen is a 12-year-old boy with spastic quadriplegia related to prematurity. He is non-ambulatory and has severe intellectual disability. His medical problems include hydrocephalus status post ventriculoperitoneal shunt, intractable epilepsy, autonomic dysfunction, oral motor dysfunction, sialorrhea, recurrent pneumonia status post tracheostomy and ventilator dependence, recurrent pneumonia, gastroesophageal reflux disease and oral motor dysfunction status post gastrojejunostomy (GJ) tube, constipation, neurogenic bladder with recurrent urinary tract infections, spasticity, bilateral hip dysplasia status post repair and scoliosis status post repair, and stereotypic movement disorder with self-injurious behavior. He is on multiple medications that are given 4 times daily. Most of the medications are liquid and are delivered through the jejunostomy tube.

Stephen lives at home with his parents and 2 older siblings, all of whom participate in his care. He has caregiver support 6 hours a day during the week, with much of the care provided by his parents and siblings outside of the covered hours. He attends school weekdays and uses respite care 2 to 4 weeks during the year at a long-term care facility. He participates in summer camp and allied therapies twice weekly in addition to therapies he receives in school.

His routine medications administered via his GJ tube include baclofen, levetiracetam, clobazam, valproic acid, topiramate, risperidone, gabapentin, clonidine, glycopyrrolate, omeprazole, erythromycin ethylsuccinate (EES), and Miralax.

He is typically admitted to the hospital 3 times annually, often requiring pediatric intensive care unit stays because of respiratory failure from recurrent aspiration pneumonia or viral illnesses. He sees several pediatric specialists, including neurology, neurosurgery, otolaryngology, dental, pulmonary, gastroenterology, urology, orthopedic surgery, and pediatric surgery. His primary care is provided by a local pediatrician in collaboration

with a complex care team at a local children's hospital that in addition to a neurodevelopmental disabilities pediatrician has a dietitian, social worker, and nurse coordinator.

## Clinical Pearls Related to Polypharmacy

Stephen's medical complexity and polypharmacy will demonstrate the following:

- During periods of viral illness CMC typically develop thickened secretions and ileus, leading to abdominal distension and feeding intolerance. Anticholinergic medications often hasten both processes and require lowering or discontinuing during periods of illnesses. Failure to recognize these interactions can prolong hospitalization or worsen clinical condition.
- Benzodiazepine medications, particularly clobazam and clonazepam, worsen sialorrhea, leading to aspiration and increased respiratory illnesses. Lowering or discontinuing these medications should be considered and if it is not possible, the addition of anti-sialorrhea medications, such as glycopyrrolate, scopolamine patch, or botox, to the salivary gland should be considered to reduce aspiration concerns.
- Valproic acid has many drug interactions and potential side effects, the most concerning of which are often unrecognized and include thrombocytopenia and pancreatitis.
- The use of EES for gastroparesis requires monitoring for prolonged QT interval.
- Medications used for autonomic dysfunction, neuropathic pain, and behavioral disorders require frequent monitoring for effectiveness and consideration for weaning because of side effects. The use of atypical antipsychotic medication, such as risperidone, requires routine monitoring for tardive dyskinesia and metabolic syndrome.

This case vignette highlights both the medical and emotional complexities in managing CMC in addition to the potential for adverse effects from polypharmacy. Often the care for CMC is fragmented and uncoordinated, leading to inefficiencies, duplication of interventions, caregiver frustrations, and poor clinical outcomes. When care is not coordinated by a central team or "quarterback," it is often managed myopically by individual subspecialists, who are more focused on medical needs related to their own specialty without appreciating "the big picture." This often contributes to polypharmacy and layering of medications. In my own personal clinical experience, chief complaints can often be related to medication side effects that go unrecognized and lead to unnecessary interventions or treatments. The unique collaboration, as suggested by Quinn et al,<sup>1</sup> between the provider and pharmacist would markedly increase awareness of these concerns and, I believe, substantially improve care.

## The Road Forward

Several key factors will improve the capability to manage polypharmacy in CMC. These include having dedicated, engaged, accessible, and knowledgeable care team members that can reliably review medications to ensure the dose and formulation are accurate and to conduct a comprehensive review of the medication regimen. Programs that are proactive rather than reactive are more likely to be more beneficial.

Most successful medication management collaborations involve dedicated teams in the inpatient and outpatient setting. Generally in the inpatient setting, pharmacists perform these reviews when certain admission criteria are met. The criteria may include:

- Number/types of medications
- Number of medical problems
- Frequency of admissions
- Participation in an outpatient complex care clinic
- Living in a PLTC facility
- Compounded medications
- Medications known to be associated with errors and/or drug interactions

In our experience, medications that are prone to error include clobazam (particularly the liquid formulation), baclofen (particularly compounded versions), clonidine (because of confusion with micrograms and milligrams as well as patch strengths and name confusion with Klonopin), benzodiazepines (particularly clonazepam and valium), and gabapentin. Careful attention to route of administration, particularly for those administered via GJ tubes, often creates confusion and contributes to errors. The GJ tubes have 2 access ports, one which administers to the stomach and the other the jejunum. These are typically used to feed more distally in patients with gastroparesis, and medications or feeds administered accidentally in the G port can lead to aspiration.

Outside of the inpatient setting, outpatient complex care teams are most suited to address concerns regarding polypharmacy, particularly if they have embedded pharmacy support. Many PLTC facilities receive their medications from larger institutional pharmacies with more focus on the adult long-term care environment. Although they may provide pharmacist consultative services, they may not be familiar with many of the unique medical problems of CMC, particularly spasticity, seizures, and feeding-related concerns, and for medications that must be sugar-free with the ketogenic diet for intractable epilepsy. The CMC expertise of the collaborative pharmacists described in Quinn et al<sup>1</sup> demonstrates how such experience led to improved medication management, a reduction in adverse events, and cost savings.

## Strategies to Deal With Shortages

Strategies to increase the number of pharmacists and pediatricians skilled in the care of CMC is an absolute

need for the optimal care of CMC and must address educational needs as well as funding support to improve salary inequities in pediatrics. Both general and pediatric subspecialties are facing declining numbers of applicants, with lower salaries believed to be a major contributing factor.<sup>9</sup> Poor reimbursement rates through Medicaid in comparison to Medicare create an inequity that underlies this phenomenon. National efforts through advocacy groups must lobby for these changes in order for meaningful change to occur.

Given that CMC are high users of health care resources, their care should be the focus of mandatory rotations and educational opportunities to improve the care literacy of these patients among pediatric and, ideally, pharmacy trainees. A national organization of CMC providers has developed such an educational curriculum.<sup>10</sup> Similarly, pharmacy students could benefit from specific postgraduate fellowships that focus on the care of pediatric CMC in the inpatient and outpatient setting. In our PLTC facility, we have a partnership with a local college of pharmacy to provide a month-long elective rotation focusing on pediatric CMC. Such rotations and fellowships would better prepare future pharmacy students to manage these patients. A national organization of PLTC facilities has guidelines for best practices and endorses regular medication reviews.<sup>11</sup>

The use of telehealth and artificial intelligence could also be used to improve access to pharmacy services despite workforce shortages. Quinn et al<sup>1</sup> provide an organizational structure for consultative services in multiple settings that could serve as a model for replication.

Lastly, payors and policymakers should endorse the role of pharmacy involvement in the care of CMC given multiple studies demonstrating improved care and reduced costs. Value-based care models using shared savings, bundled payments, or incentives could offset the cost of employing a pharmacist through demonstrated cost savings from improvements in polypharmacy management.

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