

# Caring for the Medically Complex Child

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ROBERT A. BERGAMINI, MD

**A**pproximately 3 million children in the United States are medically complex. The current health care system often fails to provide optimal care for these children just as it fails to provide appropriate support to their families. These are children who have multiple medical problems. They require specialized care from multiple providers. Many times, they and their families also need mental health services. The social needs for the children as well as their families mirror the complexity of the underlying medical issues.

Most of these children are covered by Medicaid because they were born into poverty or because their families have been impoverished by overwhelming medical costs. Medicaid and the Children's Health Insurance Program cover 48% of children with special health care needs. Annual spending is seven times higher for children who qualify for Medicaid through a disability pathway — nearly \$18,000 annually compared to about \$2,500 for a child who qualifies due to low family income.<sup>1</sup> The current health care system primarily offers fragmented care. The burden of coordinating that care falls to the families and/or caregivers, which causes increased hospitalizations, frequent visits to the emergency department and preventable readmissions. Equally important, uncoordinated care disrupts the lives of parents, siblings and other caregivers, resulting in lost days from work, lost wages and missed days from school.

The complexity of the medical needs and the inadequacies of the current system affect the lives of children and their families daily and in ways most of us would never imagine. Many of these children have scoliosis, which means they cannot

safely use a standard, commercial car seat. Custom car seats can be made — typically at a cost of about \$1500. Most Medicaid programs reimburse

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only \$500 for a custom car seat, so financially strapped families must pick up another cost. Prostheses are replaced on a schedule that is based on adult data, which ignores the fact that children, even children with handicaps and complex medical problems, grow and need to move into larger sizes before they are eligible for another one. At best, a poorly fitting prosthesis is uncomfortable. At worst, it will cause additional complications, such as skin breakdown.

The total number of children with complex



medical conditions is small, so their data are not considered in health system purchasing contracts. There are many examples of how this adds extra burdens to the complicated lives and limited resources of the children's families. A simple change in the supplier of gastrostomy-jejunostomy tubes easily cascades into a major problem. (Such tubes are used for feeding, hydration and medication administration.) The devices can fail suddenly and require emergent replacement. If a different brand is installed, different connector tubing will be required. Medicaid limits the supply of connecting tubing sets, and the sets are not interchangeable between brands. That means if a month's supply has already been issued, the family must pay for the new ones out of pocket. Certain medications administered via gastrostomy tube degrade the balloon that secures the tube in place. Medicaid and insurance companies limit replacement to one every three months. If a tube fails early, the family's only option is to visit the emergency department and have the tube replaced there.

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Children who are medically complex require constant care. Medicaid may cover private duty nursing, but many commercial insurance contracts specifically exclude this service. Families are left to provide care on their own and must make do with intermittent nursing visits. As children grow, safe transfer from a bed to a wheelchair becomes more difficult. Without sufficient help and support, this poses greater risk of injury to the caregiver and to the child. Caregiver fatigue is real and poses a health and safety risk for the entire family.

The physical needs of these children are many.

Homes must be modified to accommodate medical equipment and supplies. Hospital beds, standers, specialized wheelchairs, shower seats, ventilators and other associated equipment can necessitate major modifications to the home. Sometimes electrical service needs to be upgraded. Municipalities can require a zoning variance for a family to operate an emergency generator during a power outage, even if that generator is running life support equipment. Small generator units are difficult to maintain, and families may be unaware of the safety issues associated with their use, such as carbon monoxide fumes, fire hazards during refueling and more. Since the units are relatively portable, they can easily be stolen during power outages.

Families covered by Medicaid must learn to understand charitable assistance, accept it carefully and remain within the rules prescribed by their state. Financial support to modify a vehicle for safely transporting their child or the donation of a van with special modifications may render a family ineligible for food stamps for six months. In the same vein, home improvements can be considered gifts of substantial value and affect Medicaid eligibility and disability benefits.

Medicaid will provide transportation to medical appointments, but it will not allow a parent to bring other children along with them. Many families cannot absorb the cost of child care that would be needed for the other children to be cared for at home. A trip via ambulance to an emergency department can result in an admission, simply because the ambulance will not transport the child back home. It is also a problem that Medicaid-provided transport services demand a 72-hour set-up time.

Coordinating provider appointments is a substantial challenge to parents and other caretakers. Because surgeons have days dedicated to procedures in the operating room and other days dedicated to office hours, a child that needs services from multiple surgical specialists has to return on multiple different days based on the providers' availability. When providers are associated with different health systems, data is not readily shared and not all specialists get the relevant information they need. Duplicate tests are ordered, and children are subjected to duplicate X-rays. This not only increases costs, but it also needlessly exposes children to more radiation.

There is an inherent bias that children with medically complex conditions face. One mother



shared the following story: her daughter had several chronic medical issues, including significant developmental delay and was ill with gastroenteritis. On a good day, the child was a difficult IV start. Now, in the emergency department, dehydrated, it took 14 attempts to establish an IV. A nurse turned to the mother and said, “Don’t worry – your child is retarded so she won’t remember any of this.” Unfortunately, it is a common bias, and it ignores the basic rights of the child. It gives no credence to the unique communication that often exists between parents and their child with special needs. What a medical provider interprets as a meaningless sound can, to a parent’s ear, reflect pain, happiness, fright, laughter or sadness. Some people think that aggressive care of these children is futile; others go so far as to say it is inappropriate.

Catholic health systems are blessed to have health care-certified chaplains in many locations. Families that do not have access to properly trained chaplains can be left in a spiritual no man’s land. Advice that comes from people who are ignorant of basic medical needs and conditions or unschooled in spiritual or psychological support is not helpful and, in some instances, can be harmful to the child and family. Worse, there are still those who believe that the child’s medical conditions are punishment for the sins of the parents. Spiritually, families are devastated by such judgments and thus denied the healing that spiritual nurturing can bring.

Treatment of medically complex children usually involves many medications. Some of these medications are controlled substances. Families that struggle financially, as most of these children’s families do, often live in areas considered a “pharmaceutical desert,” which makes access to the medications that their children need far from easy. They have to use scarce resources to get the medications, and they are potential targets for theft and violence because the street value of many of the controlled substances is very high.

Children with complex medical conditions are living longer – many now surviving to adulthood. Transitioning from the role of parent to adult guardianship can be expensive, frustrating and time consuming. While applying for guardianship, families must simultaneously requalify their child for Medicaid. A review of the documentation requirements from four states reveals that the average medical interrogatory is 9.3 pages. The documentation provided to the court for guard-

ianship is generally not accepted for Medicaid, so separate documentation must be completed. Costs vary from state to state, but \$2500 is a typical minimum.

As children with complex medical conditions age, transitioning care to “adult” providers can be problematic. Pediatric facilities have age limits. Most adult providers have received little training in the problems faced by these young people. The transition itself is emotionally fraught for the young person as well as for their families — they have to leave behind the providers that many have known and trusted for two decades. The lack of willing providers for adult care at this level compounds the difficulty and increases the fragmentation of care.

Improving care for these children and their families is not impossible. It relies much more on excellent coordination and communication than it does costly equipment and complex management programs. The eight domains of care outlined by the National Consensus Project for Quality Palliative Care serve as a guide for developing a system to meet the needs of these children. The eight domains are:

1. Structure and processes of care
2. Physical aspects of care
3. Psychological and psychiatric aspects of care
4. Social aspects of care
5. Spiritual, religious and existential aspects of care
6. Cultural aspects of care
7. Care of the patient at the end of life
8. Ethical and legal aspects of care.

Achieving these goals need not be cost prohibitive. A 2016 study utilized a model that included comprehensive care coordination, expressive therapies (for example, art, music therapy), family education, respite care in and out of the home, family and bereavement counseling, pain and symptom management, and 24/7 on-call nursing support (through hospice and home health agencies).<sup>2</sup> Patients selected were those deemed likely to require at least 30 hospital days annually. This care model resulted in savings of \$3,331 per child per month. It did not require deployment of expensive monitoring equipment. Instead, case management was handled telephonically, but robust individualized case management was key to the success of the program. In addition to the cost savings, provision of care in the home setting

improved family satisfaction and patient comfort.

The care of medically complex children requires an individualized, family centered approach. There must be comprehensive care management provided by a registered nurse and/or a master's level social worker. There must be a clear plan of action for the situations most likely to occur with each particular child. Most important, there must be prompt access to medical personnel. If a parent calls because the pulse oximeter is reading 80, that parent isn't going to leave a message on voicemail but will take the child to the emergency department. If the parent can quickly contact trained medical personnel, appropriate interventions can be initiated, and the ED visit avoided. There is a clear benefit to the child. The benefit extends to the family, whose already complicated life is not further disrupted. It will be a challenge for the contracting arm of health systems to negotiate shared savings contracts that will cover the true costs of care provided.

The care of a medically complex child can consume 25%, or more, of a family's disposable income for medically related, unreimbursed expenses. This deepens the poverty of poor

families and forces other families into poverty. Focus on the poor and vulnerable is a hallmark of Catholic health care. The investment of time and resources in careful coordination of the care of medically complex children represents excellent stewardship that protect the dignity of the child, supports the family and enhances the quality of life of that child and family. This is a win for the child and family, the health system (with a good contract) and for Medicaid. It should be the standard of care for all of these children.

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#### NOTE

1. MaryBeth Musumeci and Julia Foutz, "Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending," Henry J. Kaiser Family Foundation website, Feb. 22, 2018.
2. Daphna Gans et al., "Cost Analysis and Policy Implications of a Pediatric Palliative Care Program," *Journal of Pain and Symptom Management*, 52, no. 3 (September 2016): 329-35.

## QUESTIONS FOR DISCUSSION

Robert A. Bergamini, MD, is a pediatric hematologist oncologist who cares for medically complex children. Their care is not only medically complex, but the complexity is multiplied by complications of insurance, Medicaid restrictions, poor coordination and communication among multiple providers, and family systems operating under enormous financial stress and personal fatigue.

1. Bergamini says that because the number of children with medically complex conditions is small, their data aren't considered in large purchasing contracts or Medicaid maximum payments. What does this mean for hospitals trying to support those families, hold down costs and provide high-quality care? Does your hospital have a department or designated staff person who advocates for this small, but very vulnerable population? Do you have ideas how coordinated care, pastoral care or family advocates could help?

2. There's a higher incidence of children with medically complex conditions among people who live in poverty or with other adverse social determinants of health. Talk about how caring for these children relates to the charity care your health system is able to allocate. Do you think that the children hardest hit with medical conditions in our communities warrant consideration in the development of community benefit programs or resources? Discuss practical and ethical considerations.

3. In the article's last two paragraphs, Bergamini highlights Catholic health care's focus on people who are poor and vulnerable. In the cases of medically complex children — who often live where hospitals are not — what is your health system doing? Do you have suggestions for supporting the coordination, transportation or support of families?

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