BENDING THE VALUE CURVE

Is Managed Care Better Care? The Effects of Medicaid Managed Care on Children With Medical Complexity

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Children with disabilities in Texas began to receive services through managed care Medicaid on November 1, 2016. Managed care organizations (MCOs) are often charged with the aim to reduce costs, particularly for the small but high health care–using population of children with medical complexity (CMC). We describe a child whose loss of services through managed care Medicaid resulted, ironically, in unnecessary use of health care resources.

CASE PRESENTATION

“John” was a 15-month-old male infant with a constellation of congenital anomalies, global developmental delay, insufficient oral intake with dysphagia necessitating gastrostomy tube (GT) placement, facial dysmorphisms, a bicuspid aortic valve, bilateral hearing loss, visual impairment, seizures, and a pineal gland cyst.

Because of his complex medical needs, John’s primary care physician documented a medical necessity for skilled nursing and ordered 56 hours/week of private duty nursing (PDN) services through a home health nursing agency. The Medicaid MCO involved in John’s case initially approved only 45 hours/week. This decision led to multiple appeals, peer-to-peer discussions, and a fair hearing. Ultimately, the MCO upheld the 45 hours/week ruling. Despite a decrease of only 11 hours/week in nursing hours, the mother relied on John’s family members, who were not as familiar with the necessity and administration of GT feeds, to care for him while she continued to attend school.

Subsequently, John presented to the emergency department in September with a reported 2-month history of weight loss and developmental regression. His mother and home health habilitative therapists noted regression in gross motor milestones.

Three days before admission, he experienced 6 episodes of emesis, fussiness, irritability, and weakness, and his mother noted a weight loss of 3 pounds. During this time, his mother reported several episodes of loose, nonbloody stools; decreased tolerance of GT feeds resulting in emesis; altered mental status; lethargy; cough; and nasal congestion. His mother reported that he had not been receiving speech therapy services as ordered by his primary care physician. After an additional history examination, it was discovered that his full daily GT feeding regimen was...
not being administered. He was admitted to the intermediate care unit to identify cause(s) of weight loss, monitor for refeeding syndrome, and achieve weight gain.

On admission, John appeared pale and malnourished, with loose, tented skin. He was in the less than first percentile for weight for age, less than first percentile length for age, and less than first percentile for weight for length. He was afebrile on admission, and vital signs were remarkable for elevated blood pressure. Positive signs on examination included lethargy, hypotonia, and bilateral strabismus. Cranial nerve, respiratory, circulatory, GT site, and abdominal examinations were notably normal.

Complete blood cell count, comprehensive metabolic profile, thyroid panel, and stool studies obtained after admission were unremarkable or nonspecific. Abdominal radiographs and computed tomography of the head were normal.

On admission, John received an oral rehydrating solution via GT, which was slowly titrated to the home GT regimen and, later, to a toddler formula. Caloric intake was increased as needed to optimize weight gain. A modified barium swallow study revealed aspiration with thin liquids, unchanged from the 2 previous months, requiring nectar-thick consistency liquids by mouth. A case management referral was placed to ensure home health therapies would continue after discharge.

A care conference was held on hospital day 13 with the pediatric hospital medicine team, mother, father, maternal grandmother, paternal grandmother (by phone), primary care team, physical medicine and rehabilitation, registered dietician, and genetic counselor in attendance. Care team members agreed to the following goals: weight gain of 15 g/day for 3 consecutive days, increase of GT caloric intake to follow previously prescribed home regimen, unobstructed access to home health therapies, and procurement of home equipment to achieve maximum developmental trajectory.

After presentation to the hospital, John was dehydrated and had not been receiving the prescribed GT feeding regimen at home. He was lethargic and was likely not at neurologic baseline secondary to poor nutritional intake. Certainly, the acute vomiting illness precluded adherence to the full GT regimen; however, John’s mother observed what she believed to be weight loss before this intercurrent illness. Furthermore, despite the PDN hour cut of only 11 hours/week, John was primarily cared for during these hours by family members who, per history, were not consistently adhering to the prescribed regimen. After a >2-week hospital course, John was again tolerating full GT feeds and taking food by mouth with the assistance of speech therapy. He was active and alert and had returned to neurologic baseline, regaining head control and the ability to sit and roll over.

**DISCUSSION**

**Managed Care Medicaid in Texas**

In 2013, the Texas state legislature passed legislation authorizing a transition from fee-for-service to managed care Medicaid for children receiving Supplemental Security Income and Medicaid waiver services. This legislation was implemented as the State of Texas Access Reform (STAR) Kids program in November 2016.1,2 John’s case reveals that within this system, MCO-driven denial of services and inadequate access to home health providers results in poor health outcomes and ultimately increased Medicaid spending. The STAR Kids program serves ∼180,000 children, and Texas spends $3.3 billion annually to manage care for children who are medically fragile. A January 2019 audit revealed that the number of children receiving physical therapy and occupational therapy declined by 13% after implementation of the STAR Kids program. One MCO, contracted for many regions of the state, including John’s region, denied or only partially approved 17% of PDN and therapy requests between March 2017 and February 2018. These reductions resulted in 406 appeals from families, composing >5 times the number of appeals to any other contractor.1 These for-profit health plans tout decreased health care use and reduced costs, omitting the salient point that reduction in cost does not necessarily equate with better care.

John’s story also highlights the paucity of home health therapy providers within Texas MCO networks. A delay in accessing habilitative and rehabilitative services has been associated with declining psychosocial quality of life among children with physical disabilities; therefore, timely access to these services is vital to optimizing developmental trajectories.3

**Patients With Medical Complexity**

CMC compose 5.8% of children receiving Medicaid benefits but 34% of Medicaid spending, of which 48.4% was attributed to inpatient health care and 1.6% was attributed to home health care.4,5 Ironically, Medicaid’s consistent prioritization of reimbursement for inpatient health services over home health services resulted in this child’s hospitalization despite numerous calls in the literature detailing the benefits of provision of resources in the outpatient setting. In an inspiring New Yorker article, Atul Gawande highlights the revolutionary hot-spotting method employed by Jeffrey Brenner, a Camden, New Jersey, family medicine physician.6 Brenner asserts, “Emergency-room visits and hospital admissions should be considered failures of the health-care system until proven otherwise” and contends that an investment in outpatient funds and time for high health care–using patients lowers overall health care costs in the long run.5

**Improving the System**

In an attempt to achieve the “triple aim,”7 much emphasis has been placed on reducing cost through improving measures such as length of stay and readmission rates. Because CMC present as a unique population with diverse challenges, thinking more broadly about relevant financial outcomes may prove fruitful. In addition, in experience of care, often assessed via the Consumer Assessment of Healthcare Providers and Systems or Press Ganey surveys, what is of value to families of CMC is not effectively considered. Indeed, Fayed...
et al. demonstrate the ability to recognize and reach consensus when addressing the diverse nature of family and health care providers’ perceptions of experience of care outcomes.

Promising advances focused on improving care include the Coordinating All Resources Effectively and the Collaborative Improvement and Innovation Network to Advance Care for CMC initiatives. In the Coordinating All Resources Effectively award, a family-centered approach is used to transform care coordination and introduce innovative payment models within 10 US children’s hospitals. This model has resulted in statistically significant increase in family-related health quality of life, reduction in inpatient hospital length of stay by 32%, reduction in emergency department visits, and an estimated gross savings of $3,905,547 over 1 year.9,10 Similarly, the Collaborative Improvement and Innovation Network’s goals include increasing cost-effectiveness of care. The focus of this program is also on improving quality of life for CMC and their families by fostering family engagement when enumerating deficiencies within the system.11,12

CONCLUSIONS
As health care practitioners, contracted MCOs, community-based providers, and families strive to provide the highest quality care for children with disabilities, cost remains a challenge. Ultimately, we must look beyond standard measures of cost of care and patient experience to address the unique needs of an ever-growing and increasingly complex population of children.

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