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Children With Medical Complexity And Medicaid: Spending And Cost Savings

ABSTRACT A small but growing population of children with medical complexity, many of whom are covered by Medicaid, accounts for a high proportion of pediatric health care spending. We first describe the expenditures for children with medical complexity insured by Medicaid across the care continuum. We report the increasingly large amount of spending on hospital care for these children, relative to the small amount of primary care and home care spending. We then present a business case that estimates how cost savings might be achieved for children with medical complexity from potential reductions in hospital and emergency department use and shows how the savings could underwrite investments in outpatient and community care. We conclude by discussing the importance of these findings in the context of Medicaid's quality of care and health care reform.

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Children with medical complexity are a growing population with expensive, complex, and chronic medical conditions. Such conditions often lead to functional limitations, which are often severe; substantial needs for health services to maintain health, including numerous clinicians, medications, medical equipment, therapies, and surgeries; and high health resource utilization.[1–4] Previous studies showed that about 0.4–0.7 percent of all US children (roughly 320,000–560,000 children) have medical complexity at the highest levels.[2,5–6] These children are thought to account for 15–33 percent of health care spending for all children (about $50–$110 billion annually).[5–7]

The health care system struggles to serve children with medical complexity. Community pediatricians may care for only a few of these children in their practices and may not become comfortable with managing the heterogeneous array of rare, complex health problems endured by the children. Pediatric specialists can manage these children with clinical proficiency. However, these specialists are in short supply, practice mostly in children's hospitals that are geographically distant from many of these children, and typically do not integrate care across the children's numerous providers.

Payers, including state Medicaid programs, may limit the amount, scope, and duration of covered health services for children with medical complexity. Certain services that would benefit these children and their families (such as care management and home health care) are often not offered or covered in sufficient quantity. Consequently, family caregivers often become the primary medical manager and health systems navigator for their child. The heavy caregiving burden endured by family members can negatively affect their health and well-being.[8]

In response to concerns related to finances and the quality of care, innovative models of care management are emerging to help children with medical complexity and their families. In children's hospitals—where children with medical complexity receive most of their hospital, surgical, and outpatient specialty care—clinics have been developed specifically to manage the health of these children, coordinate their care across

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numerous clinicians, and treat their urgent health problems.[9,10]

These regional hospital-based clinics are helpful. However, they may have limited capability to manage care in the children's local communities and homes. As a result, community clinics and some state Medicaid programs have increased the number of clinical personnel available to help children with medical complexity, including case managers and community health workers.[11–13] In addition, care integration innovations such as accountable care organizations are attempting to bridge hospital and community care for children with medical complexity and optimize their health care spending across settings.[14]

Guiding many of these initiatives is the theory that improving care management for children with medical complexity will result in cost savings for the health care system by reducing future expensive encounters. For example, a care manager could help promptly identify and respond to health problems experienced by a child with medical complexity over the phone, in an outpatient clinic, or in the child's home, thereby avoiding an emergency department (ED) visit or a hospitalization.

The goal of reducing health care costs through improved care management for children with medical complexity is enticing. However, reaching it will not be easy: Predicting which children will have substantial future expenditures is not particularly accurate, it will not be possible to easily reduce all of the children's future expenditures while maintaining high-quality care, and it remains unclear which care management methods for reducing cost work best.

Therefore, the success of any care management program is contingent upon two things: identifying children with medical complexity who have health problems, social and family circumstances, or other issues that can be improved with enhanced care management; and engaging these children and their families in a timely manner to reduce health care expenditures before they occur.

This article is intended to improve understanding of the opportunities and challenges for better care management and reduced health care spending for children with medical complexity who are covered by Medicaid. Using multistate and national databases, we describe the expenditures for children with medical complexity across the care continuum. We then present a business case that estimates how cost savings might be achieved for these children through reductions in hospital and ED use and shows how the potential savings could underwrite investments in outpatient and community care management.

Study Data And Methods

STUDY POPULATION In this retrospective study of administrative billing data, we used the open-source set of pediatric complex chronic conditions[15,16] to identify children with a complex and chronic health condition—the hallmark attribute of children with medical complexity—with *International Classification of Diseases*, Ninth Revision, Clinical Modification (ICD-9-CM), diagnosis and procedure codes. Used extensively to study children with medical complexity, this set of conditions comprises childhood health conditions that are expected to last longer than a year and that are associated with severe limitations in function, high morbidity and mortality, and high use of resources.[17,18]

DATA SOURCES To assess health care use and spending for children with medical complexity who were covered by Medicaid, we used two administrative databases: the Truven Marketscan Medicaid Database and the Kids' Inpatient Database (KID), from the Healthcare Cost and Utilization Project of the Agency for Healthcare Research and Quality (AHRQ).[19] For 2011 the Truven database contained medical claims across the care continuum (that is, for community-based, hospital, pharmacy, and outpatient care) for 3,686,635 Medicaid enrollees ages 0–18—including children enrolled through the Children's Health Insurance Program (CHIP)—from twelve states that represented all US geographical regions.

KID is the largest multistate database of US hospitalizations for children and includes data from 2000, 2003, 2006, and 2009.[19] For each year KID contains data about as many as 3.4 million hospitalizations for children ages 0–18 in as many as 4,121 hospitals in forty-four states. The database includes weights to produce national estimates of hospital use for children with medical complexity.

PATIENTS' CLINICAL CHARACTERISTICS Using the Truven database, we described the clinical characteristics of the study population, including the type of complex chronic conditions, the number of both complex and noncomplex chronic conditions, and eligibility for Medicaid because of a disability. We used AHRQ's Chronic Condition Indicator (CCI) classification system[20] to count the number of chronic conditions. In categorizing eligibility for Medicaid, we used the Truven database's identification of a patient with disability as "blind/disabled individual."

BUSINESS CASE For the business case, we integrated key concepts and evidence of care management for children with medical complexity with the health care cost and utilization experienced by these children in the Truven and KID databases. The online Appendix[21] provides a de-

scription of the key concepts and evidence of the business case, including examples of care management activities and approaches for children with medical complexity, amounts of reduced health care cost and utilization experienced by such children when exposed to improved care management, definitions of potentially avoidable health care encounters, and supporting citations.

Based on previous studies listed in the online Appendix,[21] we estimated a base case reduction of 10 percent, with a range of 0–20 percent, in four examples of health care encounters, three of which were potentially avoidable (thirty-day unplanned hospital readmissions, admissions for ambulatory care–sensitive conditions, and ED visits not associated with hospital admission) and one of which might be reduced (the number of days spent in the hospital across admissions).[21] We examined the trends in and current expenditures for these encounters through the KID and Truven databases, respectively.

We used the Truven database to assess the percentage of children with medical complexity whose outpatient and community care management approaches could be underwritten by cost savings from reducing the four health care encounters described above. We assessed this percentage because care management needs vary across children with medical complexity, and not all such children need improved care management.

Following previous studies listed in the Appendix,[21] we included four care management approaches in this assessment: intense care management in an outpatient, consultative, complex care clinic; care management by a community nurse; home nursing care; and postacute care.[21] We also assessed the degree to which resource use for the four health care encounters varied across and within different groups of children with medical complexity (for example, children with a neuromuscular condition versus those with a cardiovascular condition).

We assessed variation in spending for thirty-day unplanned hospital readmissions, admissions for ambulatory care–sensitive conditions, and ED visits not associated with hospital admission. We also assessed variation in the number of days spent in the hospital. We reasoned that these health care encounters may be more likely reducible (that is, potentially avoided) in children with higher versus lower levels of variation in resource use.

STATISTICAL ANALYSIS With SAS, version 9.1.3, we used the Mantel-Haenszel chi-square test to assess whether hospital resource use in the KID database stayed constant from 2000 to 2009. We defined the threshold for significance as $p < 0.05$.

LIMITATIONS Our study has several limitations. Clinical data obtained from health record reviews or patient and family interviews might more accurately identify children with medical complexity, compared with ICD-9-CM codes. The data presented in this article are cross-sectional, and thus we could not use them to assess the probability that children with medical complexity would incur future health care expenditures. The administrative data did not allow us to precisely identify which children needed improved care management. Using continuous years of KID data might be preferable in studying hospital trends for children with medical complexity, compared with the four discrete time points in a ten-year period.

In addition, the Truven database contained a variety of outpatient health care encounters aggregated into an "other" category. Most of the encounters in this category appeared to be for specialty visits.

Given the absence of a nationally representative, validated database of children with Medicaid and Truven's inability to disclose the states in its database, the generalizability of the Truven database remains unknown. We compared the demographic and clinical characteristics of hospitalized children with medical complexity who were covered by Medicaid in the Truven and nationally representative KID databases. The characteristics were very similar.

Study Results

PREVALENCE, IMPACT, AND HEALTH CARE SPENDING In 2011 children with medical complexity accounted for 5.8 percent ($n = 214,765$) of all children covered by Medicaid in the Truven database. The most prevalent chronic conditions endured by children with medical complexity were neurologic or neuromuscular (24.5 percent), congenital or genetic (22.1 percent), and cardiovascular (18.9 percent); 45.8 percent of the children had three or more chronic conditions. One-fourth of the children were eligible for Medicaid because of a disability.

Children with medical complexity accounted for 34.0 percent ($1.6 billion) of all health care spending for children with Medicaid. Spending was highly concentrated within a subset of children with medical complexity: 5 percent of these children accounted for 50 percent of total spending on children with medical complexity.

▶**OUT-OF-HOSPITAL CARE:** Out-of-hospital care accounted for 49.6 percent of total health care spending for all children with medical complexity covered by Medicaid (Exhibit 1). Outpatient specialty and other care (such as dental

EXHIBIT 1

Health Care Use And Spending For Children With Medical Complexity And Medicaid, By Health Service, 2011

Health service	Percent of children using the health service	Annual spending per child ($)	Percent of health care spending for children with medical complexity
Hospital care	13.0	5,903	47.2
Outpatient specialty and other care	66.0	3,136	25.1
Medications	89.9	1,677	13.4
Outpatient therapy	22.4	593	4.7
Emergency care	32.3	383	3.1
Primary care	59.6	275	2.2
Laboratory and radiographic testing	54.9	230	1.8
Home health care	3.2	204	1.6
Medical equipment and supplies	16.7	98	0.8

SOURCE Authors' analysis of 2011 data from the Truven Marketscan Medicaid Database.

care) accounted for 25.1 percent of spending, and medications for 13.4 percent. The remaining out-of-hospital spending for children with medical complexity covered by Medicaid was attributable to outpatient therapy, such as physical therapy (4.7 percent); primary care (2.2 percent); laboratory and radiographic testing (1.8 percent); home health care (1.6 percent); and medical equipment and supplies (0.8 percent).

▶**PRIMARY, SPECIALTY, AND HOME CARE:** Of the children with medical complexity who were covered by Medicaid, 59.6 percent had one or more primary care visits (Exhibit 1). Of the children with medical complexity who had primary care visits, the median number of annual primary care visits per child was 5 (interquartile range: 3–9; data not shown). Sixty-six percent of children had one or more other specialty or other care visits (Exhibit 1). The median number of annual specialty care visits per child among users was 2 (IQR: 1–4; data not shown). Of the children with medical complexity who were covered by Medicaid, 3.2 percent used home health care (Exhibit 1).

▶**MEDICATIONS AND MEDICAL EQUIPMENT:** Of those children, 89.9 percent had one or more prescriptions for medications filled (Exhibit 1). The median number of prescription fills for medications was 13 (IQR: 5–29; data not shown). The median number of distinct medications filled was 5 (IQR: 3–9). Common therapeutic groups of medications used by children with medical complexity included central nervous system agents (51.6 percent), gastrointestinal agents (22.7 percent), and respiratory tract agents (17.0 percent). Of children with medical complexity, 16.7 percent used medical equipment (Exhibit 1), including wheelchairs (12.8 percent; data not shown) and respiratory supplies such as oxygen and nebulizers (9.7 percent).

▶**HOSPITAL CARE:** The national KID data revealed that from 2000 to 2009, the use of Medicaid by hospitalized children with medical complexity increased from 40.5 percent to 48.4 percent. The data also showed that among children with Medicaid, there was a significant increase in the percentages of hospitalizations (from 15.3 percent to 18.5 percent), hospital days (from 32.2 percent to 38.4 percent), and hospital charges (from 42.9 percent to 49.8 percent) attributable to children with medical complexity.[21] In 2009, 2.3 percent of hospitalized children with medical complexity covered by Medicaid were discharged to a postacute care facility, and 7.3 percent were discharged with home health care.

In the 2011 data from the Truven database, hospital care accounted for 47.2 percent of the health care spending for children with medical complexity (Exhibit 1). Annual spending on hospital care per child with medical complexity ($5,903) was more than twenty times the spending on primary care and home care. Of children with medical complexity who were hospitalized (13.0 percent; Exhibit 1), three-quarters were hospitalized only once (data not shown).

BUSINESS CASE FOR COST SAVINGS AND CARE MANAGEMENT INVESTMENT As shown in Exhibit 2, cost savings varied across the four types of health care encounters proposed for reduction. The savings that could be achieved by reducing overall days spent in the hospital were by far the largest.

▶**EMERGENCY DEPARTMENT VISITS NOT ASSOCIATED WITH ADMISSION:** Of all children covered by Medicaid, those with medical complexity accounted for 12.0 percent of all ED visits that did not result in admission. Thirty-two percent of children with medical complexity had one or

more of these ED visits. For children who used the ED, the median number of such visits annually was 2 (IQR: 1–3).

ED care accounted for 3.1 percent of total health care spending for children with medical complexity (Exhibit 1). Five types of children with medical complexity (out of 1,218 types of these children in the Medicaid data set), including children with a neurologic or neuromuscular condition, accounted for 58.9 percent of all such ED expenditures, and higher-than-average variation in ED spending was observed in each of these medically complex conditions.[21]

Cost savings from a 10 percent reduction in expenditures for ED visits not associated with admission would underwrite a budget-neutral 14 percent increase in spending on primary care. Annually, that would amount to $38 available for investment in care management for each child with medical complexity (Exhibit 2).

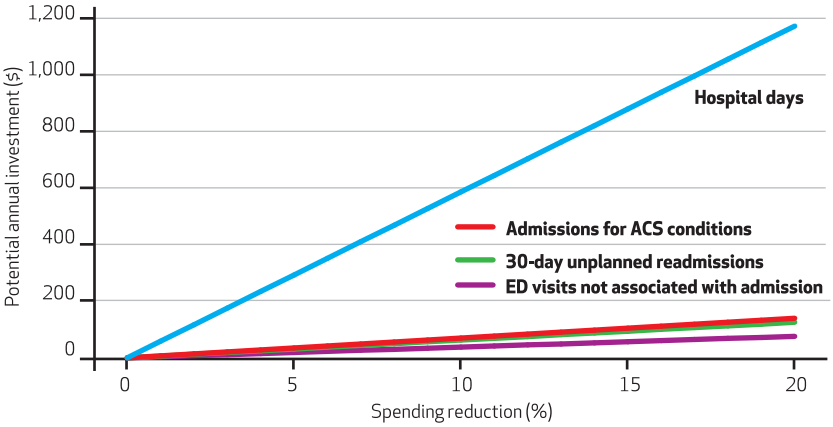
▶**HOSPITALIZATIONS FOR AMBULATORY CARE–SENSITIVE CONDITIONS:** Children with medical complexity accounted for 40.1 percent of all hospitalizations for ambulatory care–sensitive conditions in children covered by Medicaid. Twelve percent of hospitalizations for children with medical complexity were for such conditions, and these hospitalizations accounted for 7.5 percent of total Medicaid spending for children with medical complexity. Five types of medical complexity, again including children with a neurologic or neuromuscular condition, accounted for 23.6 percent of all spending on these hospitalizations, and again higher-than-average variation in spending was observed in each of these medically complex conditions.[21]

Cost savings from a 10 percent reduction in expenditures for hospitalizations for ambulatory care–sensitive conditions would underwrite a budget-neutral 26 percent increase in spending on primary care. Annually, it would produce $70 available for investment in care management for each child with medical complexity (Exhibit 2).

▶**HOSPITAL READMISSIONS:** Children with medical complexity accounted for 71.4 percent of thirty-day unplanned hospital readmissions for all children with Medicaid. Ten percent of hospitalizations for children with medical complexity were for thirty-day readmissions, and these readmissions accounted for 5.1 percent of total Medicaid spending for children with medical complexity. Five types of medical complexity accounted for 19.1 percent of spending on thirty-day readmissions for children with medical complexity.[21] As above, each of the five types had higher-than-average variation in spending, and one of the types was children with a neurologic or neuromuscular condition.

EXHIBIT 2

Potential Per Child Annual Investment Available From Reductions In Hospital And Emergency Department (ED) Expenditures For Children With Medical Complexity



SOURCE Authors' analysis of 2011 data from the Truven Marketscan Medicaid Database. **NOTE** ACS is ambulatory care–sensitive.

Cost savings from a 10 percent reduction in expenditures for thirty-day unplanned readmissions would underwrite a budget-neutral 23 percent increase in spending on primary care. Annually, that would equal $63 available for investment in care management for each child with medical complexity (Exhibit 2).

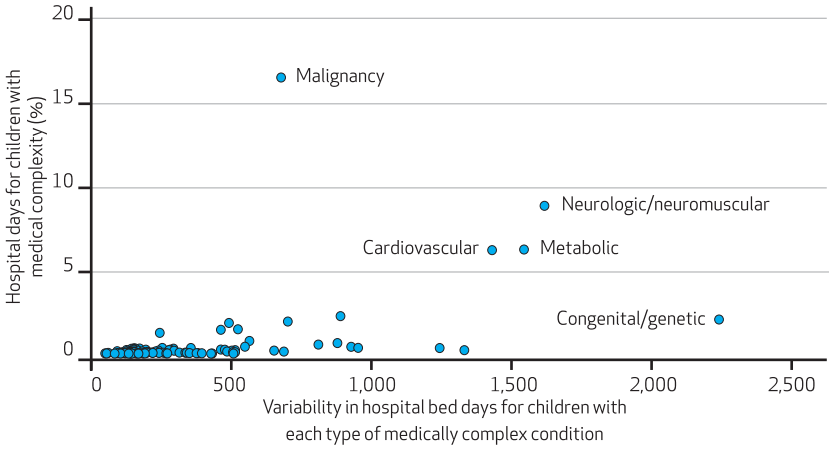
▶**HOSPITAL DAYS:** The average length-of-stay for hospitalized children with medical complexity who were covered by Medicaid was 7.2 days, with average spending of $3,928 per hospital day. Cost savings from a 10 percent reduction in hospital days would underwrite a budget-neutral 215 percent increase in spending on primary care. Annually, that would amount to $587 available for investment in care management for each child with medical complexity (Exhibit 2). Nationally, $2.9 billion would potentially be available from a 10 percent reduction in hospital days for children with medical complexity covered by Medicaid.

Five types of medical complexity, once more including children with a neurologic or neuromuscular condition, accounted for 40.5 percent of all hospital days. Higher-than-average variation in the number of days spent in the hospital was observed in each of these conditions of medical complexity (Exhibit 3).

Exhibit 4 shows what a 10 percent reduction in lengths of hospital stay could provide, and what proportion of children with medical complexity would receive each benefit, if the savings from shortening the lengths of hospital stay were appropriated to the children with medical complexity who were most in need of improved outpatient and community care management.

EXHIBIT 3

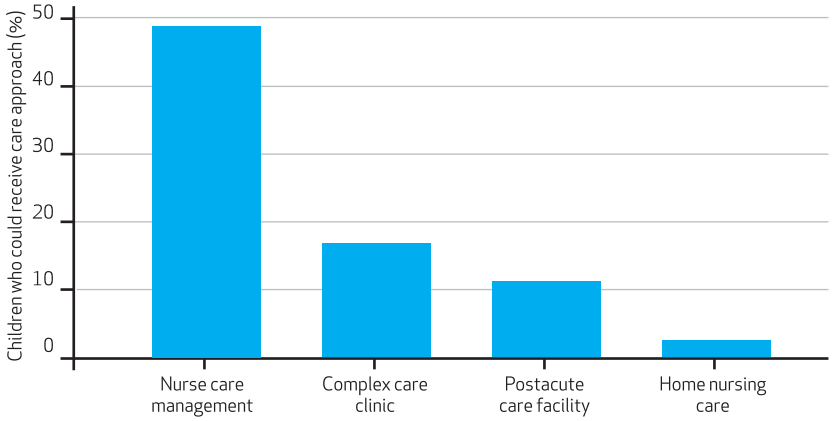
Variation In Number Of Days Spent In The Hospital, Across Types Of Medically Complex Conditions Among Children



SOURCE Authors' analysis of 2011 data from the Truven Marketscan Medicaid Database. **NOTES** The circles indicate different types of children with medical complexity based on their complex chronic conditions. The complex chronic conditions—obtained from Chris Feudtner et al., Pediatric complex chronic conditions classification system version 2 (see Note 16 in text)—were cardiovascular, gastrointestinal, hematologic or immunologic, malignancy, metabolic, neurologic or neuromuscular, other congenital or genetic, premature and neonatal, renal and urologic, respiratory, technology dependence, and transplantation.

EXHIBIT 4

Percentage Of Children With Medical Complexity Who Could Receive Four Care Management Approaches With Funds Available From A 10 Percent Reduction In Hospital Lengths-Of-Stay



SOURCE Authors' analysis of 2011 data from the Truven Marketscan Medicaid Database. **NOTES** The findings represent the results of budget-neutral investments in care management for children with complex medical conditions. "Nurse care management" is two hours per month of care management by a nurse (cost per child: $1,200). "Complex care clinic" is continuous access to intense care management in an outpatient, consultative, complex care clinic ($3,500). "Postacute care facility" is seven days of admission to such a facility ($5,250). "Home nursing care" is ten hours of such care per week ($20,800). The approaches are described further in the online Appendix (see Note 20 in text). Estimated annual costs are derived from Frerichs JK. Ideas for sustainable reform in post-acute inpatient and home care for children with special health care needs in New York. New York (NY): St. Mary's Healthcare System for Children; 2011; and from the sources in Notes 9, 12, and 24 in text.

Discussion

In an era when health care costs are of increasing concern, the care received by children with medical complexity has come under scrutiny. Indeed, as the findings presented in this article suggest, children with medical complexity have a major impact on Medicaid spending for child enrollees. This is chiefly attributable to hospital care: We found that nationally, children with medical complexity account for half of Medicaid's spending on hospital care for all children, and this proportion is increasing. We also found that, compared with hospital care spending, spending for primary care and home care for children with medical complexity is small (equal to about 8 percent of spending on hospital care), and only about 2 percent of these children use postacute care facilities after hospitalization.

We focused on potential cost savings from reducing different forms of care. We found that a given percentage reduction in overall days spent in the hospital would yield much larger cost savings than the same percentage reductions in ED visits not associated with admissions, admissions for ambulatory care–sensitive conditions, or thirty-day unplanned hospital readmissions. However, the amount of the cost savings from a reduction of overall hospital days might not be sufficient to completely underwrite the necessary investment in care management that would benefit the entire population of children with medical complexity.

Our business case analysis was based on a combination of empirical health care cost data (drawn from very large or nationally representative data sources) and assumptions regarding potential reductions in different kinds of health care utilization. The published data on these reductions for children with medical complexity show much larger reductions in hospital use (up to 80 percent)[9] than the ones that we used (up to 20 percent). Absent the use of control groups in these studies, we assumed that modest reductions would be more likely.

The Medicare-sponsored complex care initiatives associated with reductions of up to 20 percent in hospital use are intense: They include a care management team whose members participate in medical decision making with the patients' physicians, recurrently access their patients' medical records across settings, and interact frequently with their patients by phone and in person during physician visits and hospitalizations.[22,23] These care management activities, which are directly analogous to complex care clinics for children with medical complexity,[9] prevented or quickly addressed health problems that, if not contained, would have required hospitalization. They also facilitated a more

timely discharge from the hospital if the patient was admitted.

One of our key findings is that potential cost savings from a modest reduction in the number of hospital days would underwrite more intensive (and potentially more effective) approaches to care management for a smaller proportion of children with medical complexity, or less intensive (and less expensive) care management that could be delivered to a larger portion of such children. For the overall system of care management of children with medical complexity to be optimally effective, we need to know the relative effectiveness of these different approaches in terms of reducing particular types of health care utilization, and to identify which children with medical complexity have the greatest need for each approach.

Our analysis accounted only for broad diagnostic categories. However, children with medically complex neurologic or neuromuscular conditions (as shown in Exhibit 3 and the online Appendix)[21] contribute substantially to the total number of and variation in hospital days across children with medical complexity. This finding, combined with the knowledge that this population has unmet care management needs,[2] suggests that these children might benefit from targeted care management.

Our analysis did not account for the fact that many families of children with medical complexity are currently providing care management in their homes that is equivalent, in some aspects, to the level of home health care or postacute care. The efforts families must make, the out-of-pocket expenses they must bear, and the days of work they must miss to conduct these activities constitute a substantial burden.[8]

There is insufficient payment by some state Medicaid programs as well as a shortage of clinical personnel and facilities to provide home and postacute care for children.[24] This may explain, in part, why only about 2 percent of hospitalized children with medical complexity who are covered by Medicaid used postacute care (as we noted above), compared with nearly 40 percent of high-cost, hospitalized Medicare beneficiaries.[25]

From 2001 to 2011 Medicare beneficiaries experienced a remarkable reduction in spending on hospital care (from 38 percent to 24 percent), as spending increased for home health care and postacute care.[26] Further assessment is needed of the child and family benefits that could result from increased access to and use of home health care and postacute care.

Optimization of care management for the children with medical complexity who are covered by Medicaid may be more likely to occur with the standardization of health services across states.[27] States determine the coverage amount, duration, and scope of many of the health services that are essential to the health and well-being of children with medical complexity, such as home health care. As a result, substantial variation exists across states in terms of access to, quality of, and spending on health services for child Medicaid enrollees, especially children with disabilities.[28,29]

Medicaid spending affects beneficiaries' use of health services. Enrollees in states with lower Medicaid payments for outpatient care experience higher rates of hospitalization.[30]

Conclusion

This article underscored important challenges and potential opportunities related to improving care for children with medical complexity while addressing costs. Our results suggest several directions for subsequent research about children with medical complexity.

First, there is a need to better understand how health care encounters occur over time for these children. At the patient level, past or current expenditures appear to poorly predict future expenditures for these children.[31] Are there ways to identify particular children or groups of children who are more likely to benefit from enhanced care management?

Second, there is a need to compare the effectiveness of different approaches to care management for children with medical complexity, to identify potential best practices and then learn how to disseminate such practices.

Third, there is an urgent need to develop a national, publicly available database of health care costs and utilization that combines data from Medicaid and private payers. This database could be used to assess longitudinal trends in spending and health outcomes for children with medical complexity, especially in the context of predicting future expenditures and examining innovations designed to improve both the quality and efficiency of health care for these children. ■

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21 To access the Appendix, click on the Appendix link in the box to the right of the article online.

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