Estimated Nonreimbursed Costs for Care Coordination for Children With Medical Complexity

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abstract

BACKGROUND AND OBJECTIVES: Multidisciplinary care teams may improve health and control total cost for children with medical complexity (CMC). We aim to quantify the time required to perform nonreimbursed care coordination activities by a multidisciplinary care coordination program for CMC and to estimate the direct salary costs of that time.

METHODS: From April 2013 to October 2015, program staff tracked time spent in practicably measured nonbilled care coordination efforts. Staff documented the discipline involved, the method used, and the target of the activity. Cost was estimated by multiplying the time spent by the typical salary of the type of personnel performing the activity.

RESULTS: Staff logged 53 148 unique nonbilled care coordination activities for 208 CMC. Dietitians accounted for 26% of total time, physicians and nurse practitioners 24%, registered nurses 29%, and social workers 21% (1.8, 2.3, 1.2, and 1.4 hours per CMC per month per full-time provider, respectively). Median time spent in nonreimbursed care coordination was 2.3 hours per child per month (interquartile range 0.8–6.8). Enrollees required substantially greater time in their first program month than thereafter (median 6.7 vs 2.1 hours per CMC per month). Based on 2015 national salary data, the adjusted median estimated cost of documented activities ranged from $145 to $210 per CMC per month.

CONCLUSIONS: In this multidisciplinary model, care coordination for CMC required substantial staff time, even without accounting for all activities, particularly in the first month of program enrollment. Continued advocacy is warranted for the reimbursement of care coordination activities for CMC.

WHAT'S KNOWN ON THIS SUBJECT: Children with medical complexity are relatively high cost and have better outcomes and lower costs when care coordination is successful. Various models exist, but how much care is delivered beyond what is reimbursed has not been described.

WHAT THIS STUDY ADDS: The time study described in this report provides an estimate of the minimum time spent in nonbillable care coordination activities for children with medical complexity.

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Children with medical complexity (CMC) represent <1% of the US pediatric population yet account for as much as 33% of total health care spending for children[1] and 40% of pediatric hospital charges.[2] The intensity of services and costs required for optimal care of this vulnerable population places substantial burden on families and on health care systems alike.[3–5] Substantial variations exist in health care use by CMC.[6] People working within high-quality health care systems are asking how they can optimize the health and well-being of this vulnerable population while limiting high-cost spending to those areas where it will produce the most health.[7]

One approach that has shown great promise in improving health and controlling total cost of care for CMC is to create and deploy multidisciplinary care teams. Such teams exist on a spectrum from nurse care management by a practice, to disease management by external entities,[8] to the more intensive multidisciplinary management that may be provided by medical doctors (MDs), nurse practitioners (NPs), nurse coordinators, nutritionists, and social workers (SWs) at centers such as children's hospitals.[9] By matching CMC in a timely fashion to those services that will provide meaningful benefit,[10,11] care delivered by multidisciplinary teams increases the use of outpatient[12] and surgical[13] services while reducing total hospital days[13,14] and decreasing out of pocket costs to families.[5] Their value exists not only in reducing the level of care required for these children; evidence suggests that they may improve child quality of life.[15]

Multidisciplinary teams seek to match clinical services to patient needs by practicing a high degree of care coordination, defined as a process that links children and their families with appropriate services and resources in a coordinated effort to achieve good health.[16] Although care coordination programs are expected to reduce health system costs, the actual work performed by these programs can be poorly quantified and is often not reimbursed. Therefore, we aim to quantify nonreimbursed care coordination activities and to estimate the direct personnel costs associated with those activities as incurred by a multidisciplinary care coordination program for CMC.

METHODS

We conducted a time study of care coordination activities performed for children and young adults with medical complexity enrolled with the University Hospitals Rainbow Center for Comprehensive Care from January 2013 through June 2015.

Setting

The University Hospitals Rainbow Center for Comprehensive Care ("the center") is a multidisciplinary care coordination program established in 2013 and intended to address the Triple Aim[17] for community-dwelling children and young adults with medical complexity in Northeast Ohio. Following the model of tertiary care–primary care partnership established by leaders in the field,[10] the center teams with families, primary care clinicians (PCCs), and subspecialty services to optimize care and address barriers experienced by CMC and their families. Patients may be referred to the center (1) by an inpatient service at UH Rainbow Babies and Children's Hospital, a free-standing children's hospital aligned with a pediatric accountable care organization (ACO); (2) from the ambulatory setting by their PCC or specialist; or (3) by self-referral.

Patient Population

Children and young adults aged 0 to 26 years eligible for enrollment with the center experience significant neurocognitive impairment, involvement of 3 or more body systems, dependence on technology, and/or reliance on caregivers for instrumental activities of daily living (Tables 1 and 2). CMC are ineligible for the program if they are already served by a disease-specific care coordination program (eg, sickle cell, cystic fibrosis), if they are currently exercising their hospice benefits, or if they reside in a long-term care facility. There are no restrictions to enrollment on the basis of insurer. A total of 208 children and young adults with medical complexity were included in this study. At enrollment, these CMC were between 3 months and 26 years of age, with mean age of 8 years. Two-thirds demonstrated neurocognitive impairment. Three quarters relied on technology, including feeding tubes (69%); tracheostomies (15%); respiratory support devices including ventilators, continuous positive airway pressure, or bilevel positive airway pressure (9%); and other technology including central lines, urinary catheters, intrathecal baclofen pumps, vagal nerve stimulators, etc (24%).

Care Team Structure and Function

Center staff function as a care coordination team linking CMC and their PCC with coordinated specialty services. Staffing assumes enrollment of 75 to 100 patients per full-time equivalent (FTE) clinician. The team consists of 0.5 FTE general pediatricians (MDs), 2 FTE pediatric NPs, 3 FTE registered nurse (RN) case managers, 2 FTE dietitians, 2 FTE SWs, and 4 FTE medical assistants hired as family care advocates (FCAs), a novel role intended to facilitate home visits with center enrollees. Center MDs and NPs are available 24 hours per day, 7 days per week. On enrollment, the center team in partnership with the CMC and their family develops a comprehensive care plan considering findings from detailed medical, nutrition, and psychosocial

TABLE 1 Study Population: Child Characteristics

Child Characteristics	*N*	%
Sex		
Male	108	52
Female	100	48
Age at enrollment, y		
Birth to <1	27	13
1–<5	55	26
5–<11	61	29
11–<18	40	19
18+	25	12
Clinical characteristics		
No. body systems-median (range)	208	4 (3–6)
Neurodevelopmental disabilities	131	63
Cerebral palsy	98	47
Epilepsy, seizures, or convulsions	88	42
Developmental delay	14	7
Other neurologic condition	10	5
Technology dependence	162	78
Tracheostomy	32	15
Respiratory support device[a]	19	9
Feeding tube	143	69
Other technology[b]	49	24
Caregiver assistance with ADLs	194	93
Gross motor function classification[c]		
Level I–III	20	10
Level IV	36	17
Level V	93	45
Not scored	59	28

ADL, activity of daily living.

[a] Respiratory support device: ventilator, continuous positive airway pressure, or bilevel positive airway pressure.

[b] Other technology: central line, urinary catheter, intrathecal baclofen pump, vagal nerve stimulator, or other.

[c] Adapted from Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol*. 1997;39(4):214–223.

assessments. This care plan is made available to the center team, PCCs, and specialists via electronic medical record, and is used to guide care. Center clinicians see patients for both planned and urgent visits in the clinic and are available in some situations to conduct home visits. A center NP is available for consultation to inpatient teams to enroll new patients, to participate in multidisciplinary team rounds for established patients, and to assist with hospital discharge planning. Discharge from the program may occur if families move out of the ACO region or if they request program discharge.

Data Sources

Inclusion Criteria

This analysis included all recorded observations for all 208 children and young adults who enrolled with the center from January 1, 2013 (program start), through June 1, 2015. Data collection ended October 1, 2015.

Demographics

Center staff documented patient characteristics at the time of program enrollment into a study-specific SharePoint Enterprise (Microsoft Corporation, Redmond, WA) database housed on Health Insurance Portability and Accountability Act–secure, hospital-based encrypted servers.

Staff Time and Nonreimbursed Costs of Care Coordination

For each care coordination activity for each CMC, the individual performing the activity documented in the central SharePoint database their discipline (MD or NP, RN, dietitian, SW, or FCA); the method of the interaction (e-mail, telephone, chart review, video conference, or formal team review); the target of the activity (patient or caregiver; outside provider not employed at the center such as durable medical equipment suppliers, home nursing agencies, county Department of Children and Family Services, specialists, therapists, PCCs, etc; or other); and the duration (in 1 minute increments) of the activity. Direct data entry by each staff member into the SharePoint database occurred as close to real-time as possible, and no later than by the end of the work day in which the activity took place. To ensure consistency among staff, documentation of these activities was discussed as part of monthly interdisciplinary team meetings; however, the SharePoint database was not independently audited for accuracy. Activities omitted by this design included informal conversations among center staff outside the team case review setting and other communication activities such as faxing records. This study was approved by the University Hospitals Cleveland Medical Center Institutional Review Board.

Variables

Outcome Variables

The primary outcome was total time spent by center staff in care coordination activities. We estimated personnel cost by multiplying the hours in a given month spent in care coordination for a given child by the estimated hourly wage of the category of personnel performing the activity. We used estimated wages as reported by the Bureau of Labor Statistics Occupational Employment Statistics Survey, May 2015 (see Supplemental Table 5).[18] We did not assess indirect costs or benefits associated with these wages. Because MD and NP times were recorded together by center staff as a single category, hourly salary for this category was weighted to reflect program time commitments by personnel type. Additionally, any

TABLE 2 Study Population: Family Characteristics

Family Characteristics	*N*	%
Primary Insurer		
Medicaid fee for service	153	74
Medicaid managed care	21	10
Commercial	26	13
Self-pay	5	2
Missing	3	1
Household income (% FPL)		
<100	47	23
100–150	32	15
151–250	4	2
>250	53	25
Missing	72	35
Social stressors		
Receive food assistance	65	31
PIPP and/or HEAP	53	25
Single-parent household	46	22
Rely on public transportation	17	8
Receive housing assistance	16	8
Residence		
Miles from center, median (range)	208	20.9 (0–135)
Program status as of October 1, 2015, median (range) per child-mo of observation		
Active	163	16.5 (4.4–34.6)
Discharged	29	6 (0–32)
Deceased	10	4.2 (1.4–19.3)
Missing	5	—
Overall	208	14.8 (0–34.6)

FPL, federal poverty level; HEAP, Home Energy Assistance Plan; PIPP, Percentage of Income Payment Plan; —, not applicable.

in-person activities by MDs or NPs were excluded from these analyses because some might be in fact billable services depending on the setting in which they occurred.

Covariates

Child-level factors of interest included sex (male or female), age, presence of neurocognitive impairment (yes or no), insurance status, and insurance type. Family-level factors included distance of residence from center location, family socioeconomic status at 4 levels (household income as percentage of federal poverty level: 0%–100%, 101%–250%, >250%, or missing), number of adult caregivers in the household, and receipt of food assistance (yes or no).

Analyses

First, we described child- and family-level demographic characteristics for all children in the study. We next performed bivariate analyses using Pearson's χ^2 or Fisher's exact test (when expected cell size <20) to assess relationships between categorical child- and family-level characteristics, and the Wilcoxon-Mann-Whitney test to evaluate relationships between those characteristics and care coordination effort (time and cost per child per month). After estimating total time and direct personnel cost per child per month for all nonreimbursed activities, we constructed generalized linear models for each wage category to adjust cost estimates for child sex, age at enrollment, family income, and length of time enrolled in the program, censoring observations at date of program discharge, patient death, or end of the observation period. Sensitivity analyses tested for robustness of estimates to missing data and varying model assumptions. All analyses were conducted by using SAS 9.4 (SAS Institute, Inc, Cary, NC).

RESULTS

Care Coordination Activities

We recorded 53 148 care coordination activities for 205 CMC (3 enrollees contributed no activities before program discharge), an average of 19 327 activities per year and 21 activities per child per month. Our observations totaled 2586 child-months, ranging between 1 and 33 months for a given child (Table 3).

Although RNs and SWs accounted for a greater number of total activities, the clinical practitioners (MDs or NPs and dieticians) accounted for a larger proportion of time spent in such activities. Overall, all team members together spent on average 4.8 hours per enrolled child per month (median 2.3, interquartile range [IQR] 0.8–6.8) in care coordination activities (Fig 1).

Twenty percent of all recorded care coordination activities consisted of communication with a primary care MD, specialist, or ancillary provider outside the comprehensive care team. These communications required ~10 minutes each (median 7, range 0–330). Across all disciplines, an average of 61 minutes per child per month were spent in communication with other providers (median 30, range 0–846). A slightly higher (21%) proportion of these communication activities involved either the patient directly or his or her caregiver. These communications were the most time consuming, requiring median 10 minutes for each communication (range 1–330), and totaling median 48 minutes per child per month (range 0–661). The majority of care coordination activities were classified as "other," a category that included chart review and formal case review processes, weekly team-based review of new enrollees, and updates regarding acute concerns, emergency visits, and hospitalizations of established patients within the preceding week.

TABLE 3 Nonreimbursed Care Coordination Activities Performed by Staff: Number of Activities and Estimate of Cumulative Time Spent in Such Activities

Overall	N[a]	Mean	SD	Median	Minimum	Maximum
Months of observation	2586	10	7.1	9	1	33
Time (h per child-mo)	2586	4.8	6.1	2.3	0	81.4
Activities (per child-mo)	2586	20.5	22.6	13	1	163
By discipline						
Time (h per child-mo)						
MD or NP	1618	2.6	3.7	1.1	0	35.0
Social work	1865	1.4	2.3	0.5	0	26.0
Dietician	1927	1.8	2.1	1.1	0	22.1
RN	2127	1.2	1.6	0.6	0	28.7
FCA	64	1.1	1.9	0.2	0	9.9
Missing	37	0.2	0.2	0.1	0	1.0
Activities (No. per child-mo)						
MD or NP	1618	7.6	9.1	4	1	78
Social work	1865	6.1	8.0	4	1	107
Dietician	1927	7.1	7.2	5	1	79
RN	2127	7.2	7.4	5	1	58
FCA	64	3.3	3.2	2	1	16
Missing	37	1.5	1	1	1	5
By target						
Time (h per child-mo)						
Provider	1589	1.0	1.4	0.5	0	14.6
Patient	2088	1.5	1.8	0.8	0	11.0
Other	2221	3.4	4.5	1.7	0	67.7
Activities (No. per child-mo)						
Provider	1589	6.8	9.5	3	1	112
Patient	2088	5.3	5.0	4	1	46
Other	2221	14.1	15.6	8	1	98
By mode						
Time (h per child-mo)						
E-mail	1574	0.5	0.6	0.3	0	7.8
Phone	1721	0.7	0.9	0.4	0	10.3
In-person	1149	2.2	2.0	1.8	0	14.2
Video calls	87	0.2	0.3	0.1	0	1.5
Formal team review[b]	2131	2.9	4.1	1.4	0	69.4
Chart review	1605	1.0	1.2	0.6	0	9.4
Activities (No. per child-mo)						
E-mail	1574	4.6	5.6	3	1	70
Phone	1721	5.2	4.5	3	1	64
In-person	1149	4.6	6.0	3	1	40
Video calls	87	1.4	1.1	1	1	6
Formal team review[b]	2131	12.2	13.3	7	1	97
Chart review	1605	3.5	3.9	2	1	33

[a] Total child-mo of observation.

[b] Formal team review: weekly structured face-to-face meetings among members of the interdisciplinary team to discuss needs of new enrollees and address acute or emergent concerns regarding established patients in the program. This mode excludes informal or "curbside" consultations regarding a given patient.

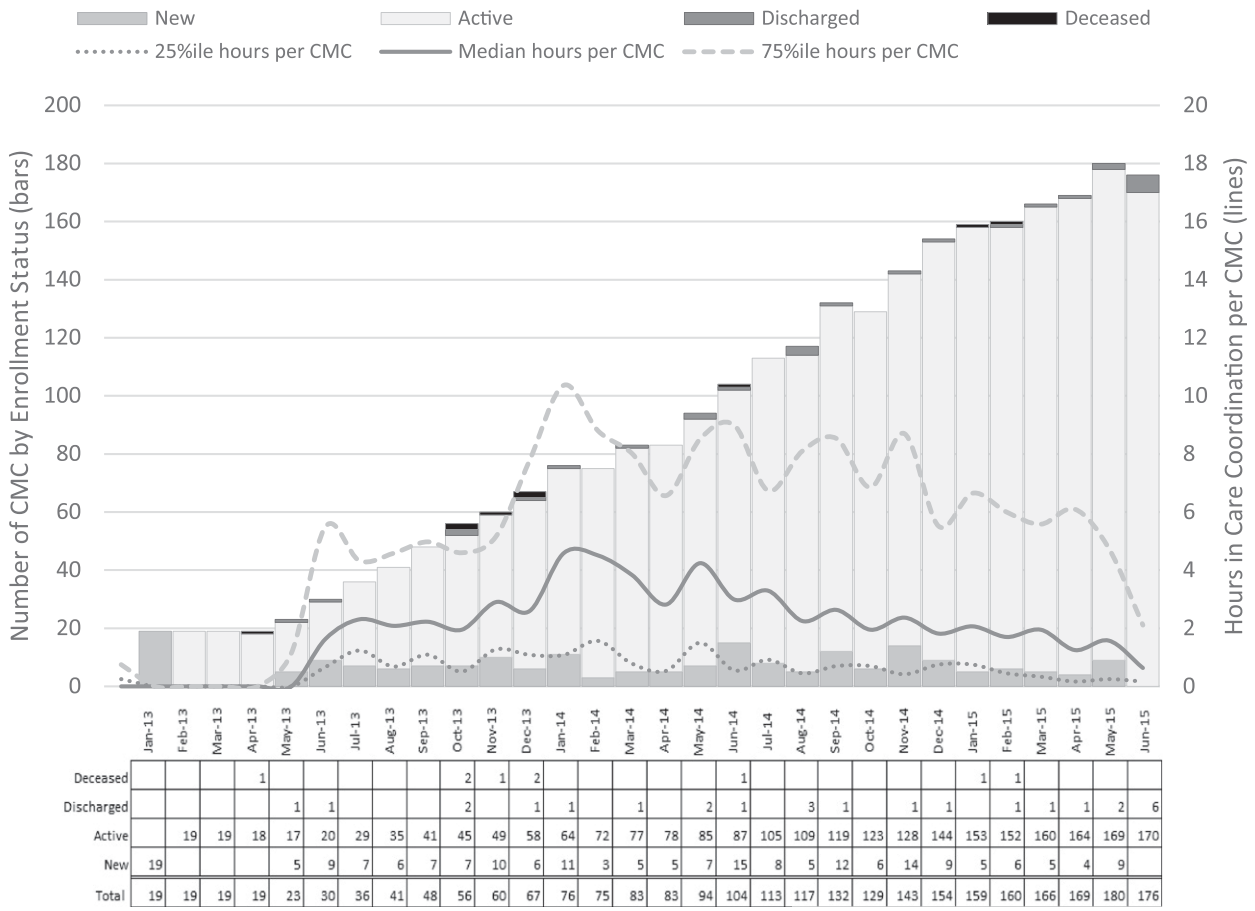
Across all disciplines, care team members spent median 100 minutes per child per month in these activities (range 0–4060).

The majority of recorded care coordination activities comprised telephone calls, chart review, team-based case review, and (for non-MD and non-NP personnel) in-person communication with patients and their families. In contrast, little time was spent on e-mail (n = 5966, median 5 minutes per activity, range 1–120) or video calls (n = 122, median 5 minutes per call, range 1–90).

We found that program staff spent substantially greater time in care coordination for children in their first month of program enrollment than they did in subsequent months. In that initial month, program staff spent median 6.7 hours per child in care coordination activities (IQR 3.7–10.6). This compares with the more modest 2.2 hours per child per month (IQR 0.7–6.4) devoted in subsequent months (Fig 2).

Estimates of Costs

Our second objective was to estimate personnel costs for these activities. We first estimated unadjusted personnel costs for care coordination. Assuming 25th percentile wages for all staff involved in care coordination, we found median cost per child per month to be $68 (IQR $19–$208), increasing to $98 (IQR $28–$300) if



	Jan-13	Feb-13	Mar-13	Apr-13	May-13	Jun-13	Jul-13	Aug-13	Sep-13	Oct-13	Nov-13	Dec-13	Jan-14	Feb-14	Mar-14	Apr-14	May-14	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14	Nov-14	Dec-14	Jan-15	Feb-15	Mar-15	Apr-15	May-15	Jun-15
Deceased				1						2	1	2						1							1	1				
Discharged					1	1				2		1	1		1		2	1		3	1		1	1		1	1	1	2	6
Active		19	19	18	17	20	29	35	41	45	49	58	64	72	77	78	85	87	105	109	119	123	128	144	153	152	160	164	169	170
New	19				5	9	7	6	7	7	10	6	11	3	5	5	7	15	8	5	12	6	14	9	5	6	5	4	9	
Total	19	19	19	19	23	30	36	41	48	56	60	67	76	75	83	83	94	104	113	117	132	129	143	154	159	160	166	169	180	176

FIGURE 1
Program enrollment status and care coordination time by calendar month, January 2013 to June 2015.

75th percentile wages were assumed. Adjusting for family income, child sex, child age at program enrollment, and length of time with the program, we found that younger child age at enrollment was significantly associated with greater personnel costs for care coordination. In addition, compared with families with income exceeding 250% of the federal poverty level, those children whose families reported income at or below 100% of the federal poverty level were more likely to incur increased costs for care coordination. These observations were consistent across models assuming hourly personnel wages at the national 25th percentile, median, and 75th percentile, respectively. In sensitivity analyses, inclusion of presence of neurocognitive impairments or distance from home to the center did not improve model fit and were not significantly associated with personnel costs.

Therefore, accounting for child age, sex, duration with program, and family income, adjusted median personnel cost per child per month was between $145 (assuming 25th percentile wages) and $210 (assuming 75th percentile wages; see Table 4).

DISCUSSION

CMC are increasingly becoming the focus of attention nationally[4,15,19,20] both because we have much to learn about how best to manage their care and because it has become increasingly apparent that these children consume a substantial proportion of the fraction of Medicaid dollars that go to children. We found that in the context of a children's hospital that is generally well staffed to care for these children, care coordination activities required conservative estimate of $145 to $210 in unreimbursed salary per child per month, not including fringe benefits, management or overhead costs. We note that our estimates are conservative, as our study design explicitly excluded important time-consuming tasks such as informal conversations among team members regarding a patient's care and appointment scheduling. It is possible that over time the development of systems to support this work (for a cost) and efficiencies borne of experience or economies of scale could alter these salary costs. Nonetheless, salaries are likely to continue to constitute a

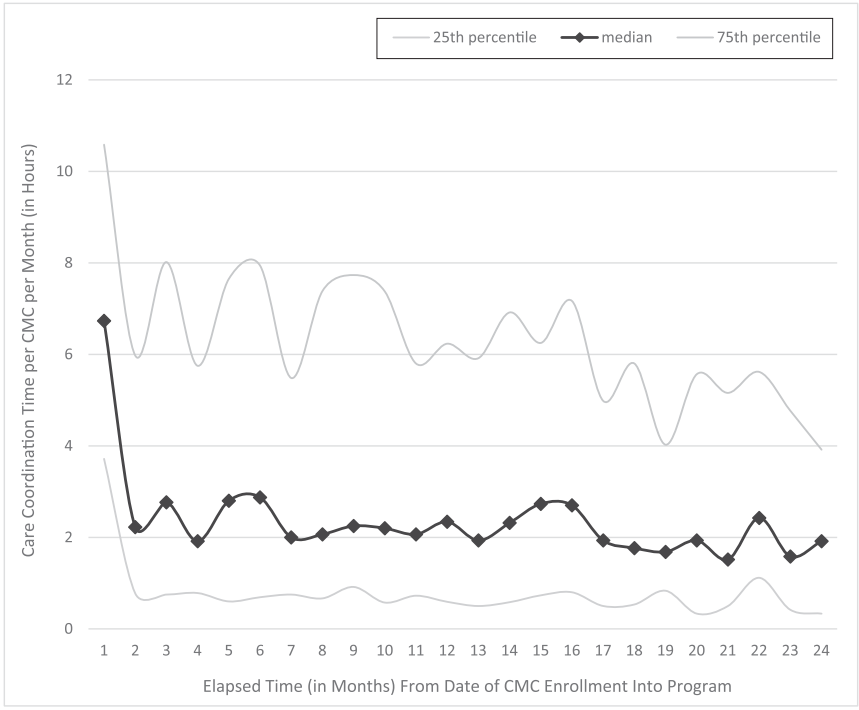


FIGURE 2
Estimated total time spent per month in nonreimbursed care coordination activities by elapsed time in months from date of CMC enrollment into the program.

significant cost to support providing coordinated care for CMC.

Care management requires work, and that work consumes resources. The value from care management may be generated through improved family- and patient-centered outcomes (including better health and greater satisfaction). Value may also be produced by increasing the efficiency of care; inappropriate services can be reduced, preventable complications avoided, and services may be provided in a more timely fashion.

One challenge is that cost-efficient and even cost-savings programs may not benefit the provider of the care coordination services. For example, assuming 75th percentile wages for clinicians and staff, we estimate a median cost of just over $200 per CMC per month in direct salary costs to provide such services ($2400 per CMC per year); the equivalent cost of 4.2 emergency department visits (at median cost $570 per visit[21]), or 1 hospital day (at $2400 per day[22]; see Supplemental Table 6). Thus, although the global outcome may be beneficial and efficient, there are market inefficiencies that allow for perverse consequences from critical perspectives; a clinical system may provide care coordination services whose efficiency reduces future revenue while a payer may benefit by avoiding future costs for no or minimal investment. Modern innovations, such as ACOs, and a population-based value framework[19] attempt to create better alignment of incentives.

Whether for assessing potential costs and savings for health planning in an innovations framework or for budgeting in a more traditional framework, the field needs a better understanding of the costs and benefits of care coordination for this vulnerable and relatively expensive population. We provide a conservative estimate of the cost component.

The time study described in this report supports planning and design. High quality and safe care for these children requires care coordination.[23–26] Our finding that new enrollees require substantially greater hours for care coordination in their first month compared with the observed subsequent relative "steady state" may help similar programs to pace admissions of new enrollees. In this era of accountability, developing payment models that align accountability, costs, and benefits will be critical for such care coordination efforts to be sustained by health care providers.[26]

TABLE 4 Estimated Direct Personnel Costs of Nonreimbursed Care Coordination Activities, Assuming 25th Percentile, Median, and 75th Percentile Hourly Wages (US Dollars per Child-Months)

	N[a]	Mean	SD	Median	IQR
Unadjusted estimated cost					
25th percentile wage	2586	150.70	213.46	68.44	19.05–207.57
50th percentile wage	2586	184.50	236.00	82.15	23.02–253.54
75th percentile wage	2586	217.79	307.45	98.24	28.02–300.15
Adjusted[b] estimated cost					
25th percentile wage	2544	150.86	53.42	145.03	111.33–187.52
50th percentile wage	2544	184.70	65.75	177.55	135.94–229.91
75th percentile wage	2544	217.99	77.03	209.73	160.89–270.90

[a] Total child-months of observation.
[b] Adjusted for family income, child age, child sex, and time since enrollment in the program, via generalized linear model with γ distribution and log link.

For its contributions, this study has important limitations. First, as an observational, uncontrolled assessment of clinical activity in a real-world setting, we have designed this study so that its biases reduce our estimate of costs. We considered only wages for time in direct services provision. We did not account for any of the additional costs required to maintain such a care program, such as program management, facility fees, and overhead. Our estimates of time and cost relied on staff logging of time spent in various activities. We speculate that when faced with pressing patient care concerns, staff may have forgone logging of those activities, further contributing to underestimation of total time expended in care coordination. Second, our program experienced substantial growth during the study period. It is therefore possible the program was over- or understaffed to meet the actual needs of CMC at various points during the study period.

We thus interpret our estimates as a low approximation of the nonreimbursed activities provided by our program. The data are specific to the design of our program; care coordination in other settings may require more or less staff. It is also likely that costs will not remain constant over time. Further research is needed to determine if our findings would hold in a more mature program. Finally, we have tried to make our estimates more general by using national salary estimates rather than local salaries. Although this study did not directly assess outcomes in terms of the Triple Aim, it does bridge the gap in the literature by estimating costs and efforts required to perform services that others have shown to be effective.[4,17,23]

CONCLUSIONS

This study aims to provide valid estimates of the unreimbursed direct salary cost of care coordination for CMC. At $145 to $210 per child per month, even this conservative estimate of costs represents a substantial investment by the institution that provides health care. Our data may be helpful for planners seeking to develop similar programs and those considering the costing of similar programs in the accountable care context, and for informing and stimulating conversations to develop evidence-informed fixes for the fee-for-service context.

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ABBREVIATIONS

ACO: accountable care organization
CMC: child(ren) with medical complexity
FCA: family care advocate
FTE: full-time equivalent
IQR: interquartile range
MD: medical doctor
NP: nurse practitioner
PCC: primary care clinician
RN: registered nurse
SW: social worker

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REFERENCES

1. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings [published correction appears in *Health Aff (Millwood)*. 2015;34(1):189]. *Health Aff (Millwood)*. 2014;33(12):2199–2206
2. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics*. 2010;126(4):647–655
3. Quigley L, Lacombe-Duncan A, Adams S, Hepburn CM, Cohen E. A qualitative analysis of information sharing for children with medical complexity within and across health care organizations. *BMC Health Serv Res*. 2014;14:283
4. Coller RJ, Nelson BB, Sklansky DJ, et al. Preventing hospitalizations in children with medical complexity: a systematic review. *Pediatrics*. 2014;134(6). Available at: www.pediatrics.org/cgi/content/full/134/6/e1628
5. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. Patterns and costs of health care use of children with medical complexity.

Pediatrics. 2012;130(6). Available at: www.pediatrics.org/cgi/content/full/130/6/e1463

6. Ralston SL, Harrison W, Wasserman J, Goodman DC. Hospital variation in health care utilization by children with medical complexity. *Pediatrics*. 2015;136(5):860–867
7. Porter ME. What is value in health care? *N Engl J Med*. 2010;363(26):2477–2481
8. Kleinman LC. A vision for disease management. *Surgical Services Management*. 1995;1(4):22–26
9. Mosquera RA, Avritscher EB, Samuels CL, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: a randomized clinical trial. *JAMA*. 2014;312(24):2640–2648
10. Kleinman LC, Kosecoff J, Dubois RW, Brook RH. The medical appropriateness of tympanostomy tubes proposed for children younger than 16 years in the United States. *JAMA*. 1994;271(16):1250–1255
11. Kemper KJ. Medically inappropriate hospital use in a pediatric population. *N Engl J Med*. 1988;318(16):1033–1037
12. Casey PH, Lyle RE, Bird TM, et al. Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children. *Arch Pediatr Adolesc Med*. 2011;165(5):392–398
13. Berman S, Rannie M, Moore L, Elias E, Dryer LJ, Jones MD Jr. Utilization and costs for children who have special health care needs and are enrolled in a hospital-based comprehensive primary care clinic. *Pediatrics*. 2005;115(6). Available at: www.pediatrics.org/cgi/content/full/115/6/e637
14. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med*. 2007;161(10):937–944
15. Simon TD, Mahant S, Cohen E. Pediatric hospital medicine and children with medical complexity: past, present, and future. *Curr Probl Pediatr Adolesc Health Care*. 2012;42(5):113–119
16. Council on Children With Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5). Available at: www.pediatrics.org/cgi/content/full/133/5/e1451
17. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff (Millwood)*. 2008;27(3):759–769
18. US Bureau of Labor Statistics. Occupational employment statistics. Available at: https://data.bls.gov/oes. Accessed November 2, 2015
19. Chen AY, Schrager SM, Mangione-Smith R. Quality measures for primary care of complex pediatric patients. *Pediatrics*. 2012;129(3):433–445
20. Berry JG, Agrawal RK, Cohen E, Kuo DZ. *The Landscape of Medical Care for Children With Medical Complexity*. Overland Park, KS: Children's Hospital Association; 2013
21. Agency for Healthcare Research and Quality. Emergency room services: Mean and median expenses per person with expense and distribution of expenses by source of payment: United States, 2014. Medical expenditure panel survey household component data. Generated interactively. Available at: https://meps.ahrq.gov/mepsweb/data_stats/tables_compendia_hh_interactive.jsp. Accessed November 27, 2018
22. Kaiser Family Foundation. Hospital adjusted expenses per inpatient day by ownership. 2015. Available at: https://www.kff.org/health-costs/state-indicator/expenses-per-inpatient-day-by-ownership/. Accessed February 2, 2018
23. Berry JG, Agrawal R, Kuo DZ, et al. Characteristics of hospitalizations for patients who use a structured clinical care program for children with medical complexity. *J Pediatr*. 2011;159(2):284–290
24. Gidengil C, Parast L, Burkhart Q, et al. Development and implementation of the family experiences with coordination of care survey quality measures. *Acad Pediatr*. 2017;17(8):863–870
25. Hessels AJ, Agarwal M, Saiman L, Larson EL. Measuring patient safety culture in pediatric long-term care. *J Pediatr Rehabil Med*. 2017;10(2):81–87
26. Kleinman LC. Conceptual and technical issues regarding the use of HEDIS and HEDIS-like measures in preferred provider organizations. *Med Care Res Rev*. 2001;58(suppl 4):37–57

Supplemental Information

SUPPLEMENTAL TABLE 5 Estimated Staff Wages Used for Cost Calculations (US Dollars)

Staff Type	BLS Description of Staff Position[a]	SOC Code	Hourly 25th Percentile Wage	Hourly Median Wage	Hourly 75th Percentile Wage
MD	Pediatricians, general	29–1065	59.14	81.32	90[b]
NP	NPs	29–1171	42.98	49.64	58.24
RN	RNs	29–1141	27.29	33.42	41.18
RD	Dietitians and nutritionists	29–1031	23.93	28.13	33.62
SW	Health care SWs	21–1022	22.67	27.86	33.92

Adapted from: Bureau of Labor Statistics. Occupational employment statistics survey. Available at: http://data.bls.gov/oes. Accessed November 2, 2015. BLS, Bureau of Labor Statistics; RD, registered dietitians and nutritionists; SOC, standard occupational classification.

[a] Industry: Offices of Physicians.

[b] Hourly 75th percentile wage for general pediatrics top-coded in BLS at $90.

SUPPLEMENTAL TABLE 6 Relative Costs of Hospital Days and Emergency Department Visits Compared With Adjusted Estimated Costs for Care Coordination (US Dollars)

BLS Hourly Wage Category	Cost ($) per CMC per mo	Cost ($) per CMC per y	Hospital d,[a] *N*	Emergency Department Visits,[b] *N*
25th percentile	109.49	1313.88	0.55	2.31
	144.15	1729.80	0.72	3.03
	194.11	2329.32	0.97	4.09
50th percentile	133.53	1602.36	0.67	2.81
	176.17	2114.04	0.88	3.71
	238.20	2858.40	1.19	5.01
75th percentile	157.97	1895.64	0.79	3.33
	207.80	2493.60	1.04	4.37
	280.23	3362.76	1.40	5.90

Adjusted for family income, child age, child sex, and time since enrollment in the program, via generalized linear model with γ distribution and log link. BLS, Bureau of Labor Statistics.

[a] Assuming $2400 per hospital inpatient day at not-for-profit hospital.[22]

[b] Assuming $570 per emergency department visit for children and young adults ages 0–26 years.[21]