

Care Coordination Program for Children With Complex Chronic Conditions Discharged From a Rural Tertiary-Care Academic Medical Center

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ABSTRACT

OBJECTIVES: Hospital discharge offers an opportunity to initiate coordination of follow-up care, preventing readmissions or emergency department (ED) recidivism. We evaluated how revisits and costs of care varied in a 12-month period between children in a care coordination program at our center (enrolled after hospital discharge with a tracheostomy or on a ventilator) and children with complex chronic condition discharges who were not enrolled.

METHODS: Children ages 1 to 17 years were retrospectively included if they had a hospital discharge in 2017 with an *International Classification of Diseases, 10th Revision* code meeting complex chronic condition criteria or if they were in active follow-up with the care coordination program. Revisits and total costs of care were compared over 2018 for included patients.

RESULTS: Seventy patients in the program were compared with 56 patients in the control group. On bivariate analysis, the median combined number of hospitalizations and ED visits in 2018 was lower among program participants (0 vs 1; $P = .033$), and program participation was associated with lower median total costs of care in 2018 (\$700 vs \$3200; $P = .024$). On multivariable analysis, care coordination program participation was associated with 59% fewer hospitalizations in 2018 (incidence rate ratio: 0.41; 95% confidence interval: 0.23 to 0.75; $P = .004$) but was not significantly associated with reduced ED visits or costs.

CONCLUSIONS: The care coordination program is a robust service spanning the continuum of patient care. We found program participation to be associated with reduced rehospitalization, which is an important driver of costs for children with medical complexity.

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Among children in the United States, 19% have special health care needs (SHCNs), defined by the Maternal and Child Health Bureau as conditions requiring specialized health care or more health care services than would be required by a typical child.¹ Complex chronic conditions (CCCs), such as cerebral palsy, muscular dystrophy, congenital heart disease, or renal failure, are a prominent contributor to SHCNs, requiring follow-up care by a broad range of pediatric specialties.^{2,3} Hospitalizations among children with CCCs may occur because of a wide range of procedures or complications; and among children discharged from the hospital, CCCs are associated with increased hospital costs and increased risk of readmissions and visits to the emergency department (ED).^{2,4,5} However, coordination of care for children with CCCs has been shown to reduce these revisits by providing primary and specialty care services that comprehensively address these children's health needs in an outpatient setting.⁶ Consequently, care coordination initiatives have been emphasized as elements of Accountable Care Organizations and other programs aiming to control the cost of care for children with SHCNs or CCCs.

In a recent study, authors found that 14% of US children with SHCNs had unmet needs for care coordination.⁷ For children admitted to the hospital, the discharge process offers a unique opportunity to initiate coordination of follow-up care and prevent readmissions or ED revisits.⁸ At this university-affiliated medical center, a tertiary-care regional hospital, the Center for Children with Complex and Chronic Conditions (C5) program was established in 2008 to initiate care coordination for children with CCCs in an inpatient transitional care unit and continue this coordination in a multidisciplinary outpatient C5 clinic, with home visits by a designated care coordination team. Situated in a large, rural geographic area of the southeastern United States, the C5 program serves children who may otherwise lack access to community pediatricians able to provide comprehensive care for CCCs. We aimed to evaluate the impact of this program on readmissions, ED revisits, and

total costs, using a retrospective comparison of these outcomes over a 12-month period between 2 groups: children enrolled in C5 and children who had a hospital discharge meeting CCC criteria but were not enrolled in the C5 program.

METHODS

C5 Program

The C5 program aims to deliver a system of care for a vulnerable patient population that is patient and family centered, seamless, and proactive. During the review period, the program enrolled children with chronic respiratory insufficiency requiring life-sustaining technological support (tracheostomy or mechanical ventilation) and specialty care interventions. The program team is led by a medical director and a nurse practitioner and includes a registered nurse, respiratory therapist, and social worker. While children are hospitalized in the transitional care unit, transition care coordinators educate caregivers about the care required after discharge. After discharge, C5 program activities include quarterly home visits, providing outpatient care in a dedicated multidisciplinary clinic and coordinating visits to primary care pediatricians, pediatric subspecialists, health services agencies, and government agencies. The program also provides families with the

ability to contact clinical or social work staff at any time and connects families with nursing and medical equipment companies involved in the patient's care. Transition care coordinators document all care coordination activities within the patient's electronic health record and communicate securely with providers regarding a patient's clinical condition during home visits, school visits, or ambulatory appointments. This communication helps prevent unnecessary ambulance transports and admissions to community hospital EDs that are not prepared to manage medically complex children. At any time, the program provides inpatient and outpatient services to ~50 medically fragile and technology-dependent children in eastern North Carolina.

Study Cohort and Comparison Group

To assess the outcomes of C5 program participation, we aimed to compare C5 patients with a similar group of children with high health care needs and risk of hospitalization who were not enrolled in the C5 program. The construction of the C5 and control group cohorts for this study are summarized in Fig 1. The C5 group included children age <18 years who had a note filed by the C5 care coordinator during 2017 (ie, were in active follow-up by C5 during

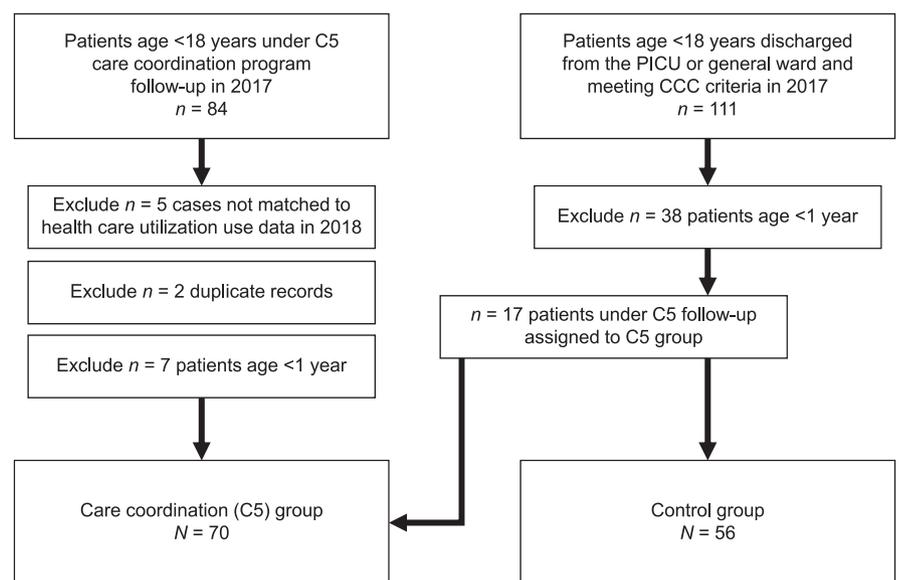


FIGURE 1 Cohort inclusion and exclusion criteria.

TABLE 1 Comparison of Patient Characteristics (Measured in 2017) and Outcomes (Measured in 2018) by Study Group

Variable	C5 Participants (N = 70) Median (IQR) or n (%)	Control Group (N = 56) Median (IQR) or n (%)	P
Patient characteristics assessed in 2017			
Age, y	7 (3–12)	7 (4–13)	.545
Sex			.935
Male	42 (60)	34 (61)	
Female	28 (40)	22 (37)	
Race and/or ethnicity			.270
Non-Hispanic African American	41 (59)	25 (45)	
Non-Hispanic white	21 (30)	24 (43)	
Other race and/or ethnicity	8 (11)	7 (13)	
Major comorbidities ^a			
Cerebral palsy	29 (41)	12 (21)	.017
Seizure disorder	21 (30)	14 (25)	.534
Congenital heart disease	8 (11)	4 (7)	.546
Hydrocephalus	5 (7)	7 (13)	.309
Chronic lung disease	7 (10)	1 (2)	.075
Anoxic brain injury	6 (9)	4 (7)	>.999
Cancer	1 (1)	8 (14)	.010
Surgical history ^a			
Tracheostomy	37 (53)	18 (32)	.020
Gastrostomy tube	48 (69)	30 (54)	.085
Nissen procedure	16 (23)	8 (14)	.223
Ventriculoperitoneal shunt	8 (11)	7 (13)	.854
Insurance coverage			.965
Private	8 (11)	7 (13)	
Medicaid and/or Medicare	59 (84)	47 (84)	
Other or none	3 (4)	2 (4)	
CCC categories ^{a,b}			
Technology dependent	—	31 (55)	—
Neuromuscular	—	26 (46)	—
Gastrointestinal	—	15 (27)	—
Renal	—	11 (20)	—
Respiratory	—	6 (11)	—
Malignancy	—	6 (11)	—
Cardiovascular	—	3 (5)	—
Hematologic or immunocompromised	—	2 (4)	—
Metabolic	—	1 (2)	—
No. CCC present			
1	—	45 (80)	—
2	—	8 (14)	—
3	—	3 (5)	—
Health care use in 2017			
Hospitalizations	0 (0–1)	2 (1–4)	<.001
ED visits	0 (0–1)	0 (0–1)	.076
Hospitalizations and ED visits	1 (0–2)	2 (1–5)	<.001

that year). All children in the C5 group had a previous hospitalization in our children's hospital but not necessarily in 2017. Children with any CCCs have been previously analyzed as a pediatric population at increased risk of hospitalization and incurring higher health care costs.^{2,4,5} Therefore, the control group included children age <18 years if they were discharged from the PICU or general ward in 2017 with an *International Classification of Diseases, 10th Revision* (ICD-10) code meeting criteria for CCC as defined by Feudtner et al.³ Stata software (Stata Corp, College Station, TX) code provided with the article by Feudtner et al³ describing the CCC criteria was applied to ICD-10 codes to determine control group eligibility. Most of these patients were not enrolled in the C5 program; however, in a few cases, C5 patients had a hospital discharge during 2017 that met CCC criteria. In our study, these patients were assigned to the C5 group. In both groups, children <1 year of age were excluded from the analysis. Among encounters deemed eligible for this analysis, the earliest CCC discharge (control group) or C5 note (intervention group) during 2017 was analyzed as the index encounter.

Outcomes

Outcomes for this study were extracted from the electronic medical record (EMR) covering hospitalizations and ED visits at our health system during the review period. Although the health system and EMR span multiple hospitals and EDs throughout the region, the only pediatric hospital and pediatric ED are located at the system's main campus. Rehospitalizations and ED visits were assessed over a 12-month period (January to December 2018). This period was selected to provide comparable data to previous studies in which authors evaluate 12-month health services use among children with chronic health conditions.^{7,9,10} Total costs of care (including both acute and nonacute care visits to facilities in the hospital system) were determined over the same period by combining direct and indirect costs over this period. Direct costs, both fixed and variable, are those costs attributed to the patient encounter that are

TABLE 1 Continued

Variable	C5 Participants (<i>N</i> = 70) Median (IQR) or <i>n</i> (%)	Control Group (<i>N</i> = 56) Median (IQR) or <i>n</i> (%)	<i>P</i>
Patient outcomes assessed in 2018			
Health care use in 2018			
Hospitalizations	0 (0–0)	0 (0–1)	.025
ED visits	0 (0–0)	0 (0–1)	.254
Hospitalizations and ED visits	0 (0–1)	1 (0–3)	.033
Total cost of care, Thousands, \$ ^c	0.7 (0–3.8)	3.2 (0–27.9)	.024

—, not applicable.

^a Categories are not mutually exclusive.

^b Data available only for control group.

^c Including all hospital system encounters not limited to hospitalizations and ED visits.

directly related to providing a patient's care. An example of a direct fixed cost would be the children's hospital power bill, and a direct variable cost would be the supply cost attributed to the patient's care. Indirect costs are allocated proportionately across all patient encounters, with examples being corporate costs such as human resources labor or information technology infrastructure.

Covariates

Covariates included patient demographics (age, sex, race and/or ethnicity), insurance coverage, and the number of hospitalizations or ED visits in 2017. Additional variables analyzed for the study included major comorbidities and surgical history (as of 2017); for patients in the control group, variables included the number and types of CCCs classified according to the algorithm by Feudtner et al.⁵ Comorbidities and previous surgeries as of 2017 were manually reviewed by the authors because patients in the 2 groups had varying types and number of encounters during 2017 (eg, not all patients in the C5 group were hospitalized during that year). The most common diagnoses or procedures were selected for inclusion as covariates in the analysis. Statistical analysis was used to compare hospitalization rates, ED revisit rates, costs, and patient characteristics according to C5 program participation by using rank-sum tests, χ^2 tests, or Fisher's exact tests, as appropriate to the distribution of each variable. Multivariable Poisson regression models were used to model the number of hospitalizations and ED revisits according to

C5 program participation and other covariates. For regression analysis, cost data were log transformed and evaluated by using multivariable linear models. Data analysis was performed by using Stata/SE 15.1, and $P < .05$ was considered statistically significant.

RESULTS

During 2017, the C5 program managed 84 patients, as determined by reviewing follow-up notes documented in the electronic health record of patients enrolled in the program. We excluded 5 patients who could not be matched to health care use data during the review period, 2 duplicate records, and 7 patients age < 1 year, leaving a total of 70 C5 patients in the analysis. The group was compared with 56 patients who had a hospital discharge meeting CCC criteria in 2017 and were not managed by the C5 program during that year. In the overall sample, the median age was 7 years (interquartile range [IQR]: 3–12), and 60% of patients were male. The majority of patients (52%) were non-Hispanic African American, followed by non-Hispanic white (36%) and patients of other race and/or ethnicity (12%). Eighty-four percent of patients had public health insurance.

Patient characteristics (assessed in 2017) are summarized by study group in Table 1. In the control group, 80% of patients had only one type of CCC, and 55% met the criteria for technology-dependent CCC. Common CCCs in the control group (determined from ICD codes) included neuromuscular (46%), gastrointestinal

(27%), and renal (20%) conditions. The most common comorbidities in both groups (determined by manual chart review) were cerebral palsy and seizure disorder, and the most common surgical procedures were tracheostomy and gastrostomy tube insertion. Although CCCs based on hospital discharges were not assessed for C5 program participants (because not all patients in this group had a hospital admission in 2017), Table 1 reveals that this group represented a highly medically complex cohort, with a high prevalence of major comorbidities (eg, 41% of patients had cerebral palsy, and 30% had seizure disorder) and surgical intervention (eg, 69% had a gastrostomy tube, and 53% had a tracheostomy). On bivariate statistical analysis, prevalence of the most common comorbidities and surgical interventions was either statistically indistinguishable between the 2 groups or more common in the C5 group.

In 2018, patients enrolled in the C5 program had fewer total revisits to the hospital and ED than patients in the control group (median 1 and IQR: 0–3 versus median 0 and IQR: 0–1; $P = .033$). Histograms of revisits by type are shown in Fig 2, with the difference between groups reaching statistical significance for rehospitalization ($P = .025$) but not revisits to the ED ($P = .254$). Median total costs of care in 2018 were > 3 times as large in the control group as in the C5 group (\$3200 [IQR: 0–\$27 900] vs \$700 [IQR: 0–\$3800]; $P = .024$).

To adjust for the difference in baseline characteristics (eg, increased number of hospital encounters in 2017 for the control group), we performed multivariable regression analysis of the study outcomes as summarized in Table 2. (Detailed regression model results are shown in Supplemental Tables 3 through 6). On multivariable analysis, C5 program participation was associated with a reduced number of hospitalizations (incidence rate ratio [IRR]: 0.41; 95% CI: 0.23 to 0.75; $P = .004$) but no reduction in ED revisits or total cost of care. The association between the C5 program and the total number of revisits was favorable (fewer revisits in the C5 group), but did not reach statistical

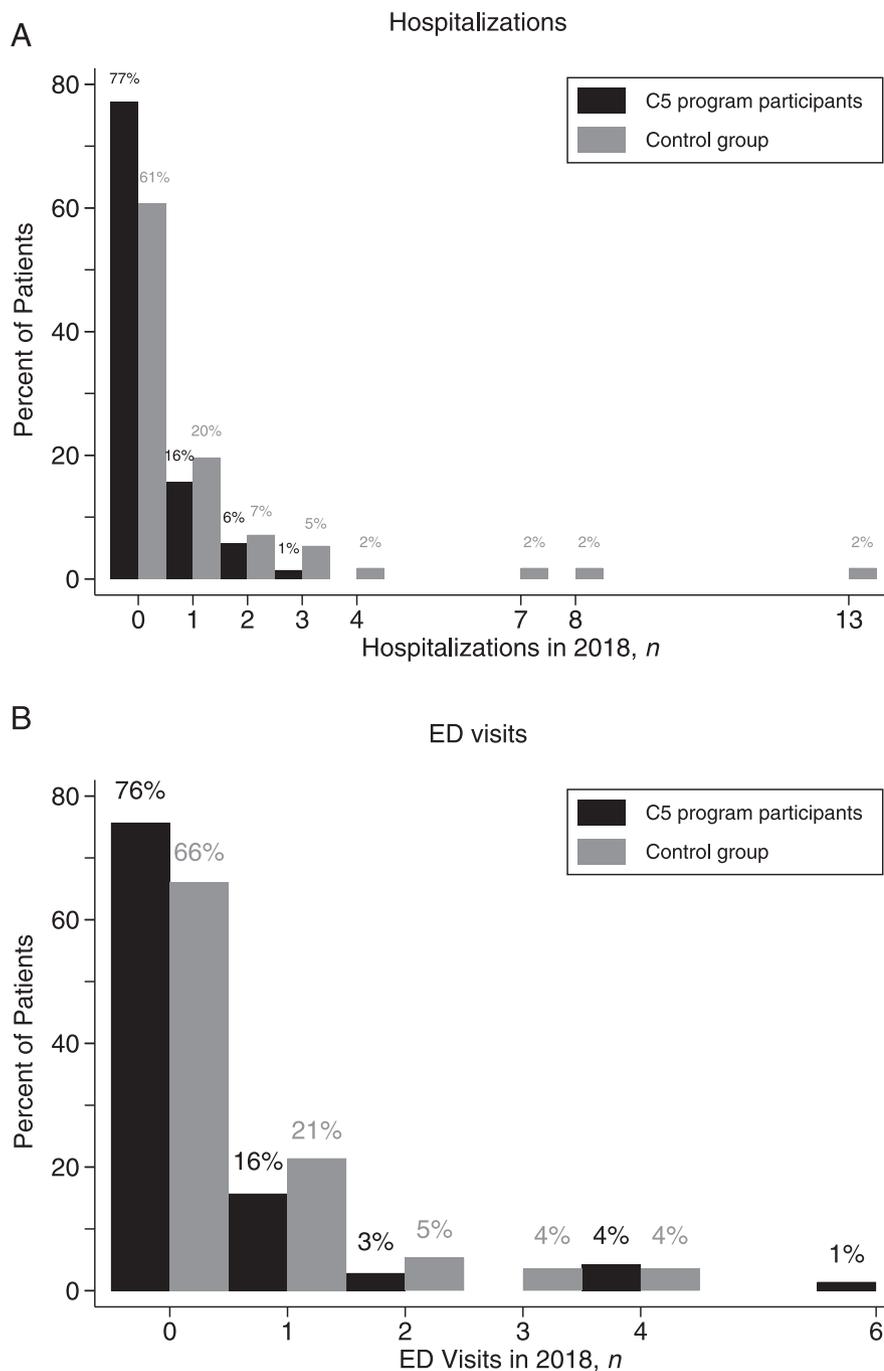


FIGURE 2 Histogram plots comparing hospitalizations and ED visits in 2018 according to C5 care coordination program participation. A, Hospitalizations. B, ED visits.

significance (IRR: 0.67; 95% CI: 0.44 to 1.01; $P = .054$).

DISCUSSION

Care coordination for children with medical complexity has been proposed to reduce avoidable resource use and improve health-

related quality of life.^{11,12} However, demonstrating the value of care coordination interventions is challenging because these outcomes are multifactorial and because delivery of care coordination prioritizes the sickest of the sick. At this university-affiliated medical center, the

C5 program initiated care coordination for medically complex children as they transitioned from an inpatient setting to an ambulatory setting. Our clinical experience suggested that the C5 program improved quality of life for children and their families while reducing unnecessary hospitalizations. In comparison with patients meeting CCC criteria at the time of a recent hospital discharge but not enrolled in the C5 program, patients receiving care coordination by the C5 program had fewer rehospitalizations during a 1-year review period and, on bivariate analysis, reduced median total costs of care.

As health care financing transitions away from fee-for-service models toward population health, it has become increasingly relevant to evaluate financial data at the patient level to identify cost-effective practices and opportunities for cost savings. Care coordination for children with complex medical conditions provides an example of how additional care delivered via ambulatory visits, home visits, and remote consultation can reduce acute care visits. After multivariable adjustment, we confirmed that C5 program participation was associated with fewer rehospitalizations, which are a major driver of health care costs for children with medical complexity, but we did not find a statistically significant difference in total costs of care. One potential area for future improvement may be the relationship between C5 program participation and ED visits. Historically, patients managed by the program have been advised to go to the ED by a provider outside of the C5 team. Improved communication and comfort with managing these patients could help reduce ED visits and potential readmissions. Future evaluation of the C5 program could also prospectively track both health care use as well as quality and longevity of life to identify whether care coordination services are correlated with C5 transition care coordination.

A growing body of literature has sought to categorize predictors of health care use and costs among children with medical complexity to improve risk stratification within this patient population.^{12,13} As

TABLE 2 Summary of Multivariable Regression Models Estimating Association Between C5 Care Coordination Program Enrollment and Study Outcomes in 2018

Study Outcome	C5 Program Participation			P
	IRR ^a	Coefficient ^b	95% CI	
Hospitalizations in 2018	0.41	—	0.23 to 0.75	.004
ED visits in 2018	1.18	—	0.61 to 2.27	.622
All revisits in 2018	0.67	—	0.44 to 1.01	.054
Total cost of care in 2018, log \$	—	−1.18	−2.84 to 0.47	.160

All models control for patient age, sex, race and/or ethnicity, insurance coverage, comorbidities, surgical history, and number of hospitalizations or ED visits in 2017. Detailed model results are shown in Supplemental Tables 3 through 6. —, not applicable.

^a IRR represents how a 1-unit change in the independent variable is associated with change in the count of acute care visits. For example, IRR = 1.5 implies a 50% increase in the number of visits for a 1-unit increase in the independent variable.

^b Coefficients represent how a 1-unit change in the independent variable is associated with change in log-transformed total costs of care in 2018. For example, a coefficient of 0.5 implies an increase of $(\exp[0.5] - 1) \times 100 = 65\%$ in the cost of care for a 1-unit increase in the independent variable.

reported by Leary et al,¹⁴ previous hospital admissions and previous ED visits are a reliable predictor of future readmission risk. In this study, the predicted number of hospital admissions in 2018 increased by 17% (IRR: 1.17; 95% CI: 1.07 to 1.29; Supplemental Table 3) for each additional ED visit or hospitalization in 2017 when analyzing the pooled sample of C5 participants and children with CCC discharges who formed the control group. With past research identifying socioeconomic disparities in hospital readmission,¹⁵ this dependence of future admission risk on the history of past admissions could reflect lack of access to outpatient and home-based care due to socioeconomic disadvantage. Previous work has demonstrated that socioeconomic factors influence children's hospital readmission rates and families' experience with the transition from hospital to home.^{16,17} Further work is needed to understand how socioeconomic disadvantage may affect families' ability to participate in care coordination programs and the efficacy of these programs.

Conclusions were informed but also limited by the study setting and analytic approach. Most importantly, it was a challenge to identify an appropriate control group for C5 program participants given that a pre-C5 cohort could not be identified (because of the program's long history at our institution and evolving criteria for program participation). Additionally, because

C5 generally continues following patients after enrollment, we could not analyze the impact of the program by contrasting periods of program participation and nonparticipation.¹⁸ A further limitation was the retrospective nature of the study and the use of EMR data from a single health system. Although this health system included the only pediatric ED and children's hospital in the region, it is possible that children in the study could have been admitted or seen in the ED at other facilities, potentially leading to an undercount of acute care visits. Results may be different for similar programs in urban settings, where there is a higher density of health care facilities, not all of which might be in the same health system. Lastly, although children with hospital discharges meeting CCC criteria were deemed to be conceptually similar to C5 enrollees, the analysis was limited by using only 1 year of data to determine study eligibility and the next year of data to query study outcomes. Given the rarity of hospital readmissions in pediatrics,¹⁹ even among high-risk children, this may have limited the statistical power of the analysis and specifically the ability to demonstrate cost savings attributable to the C5 program after multivariable adjustment.

With increased emphasis on population health among children's hospitals, the C5 program has evolved into a comprehensive and nimble service providing transition care coordination to children with medical complexity across a

rural 29-county region in the southeastern United States and spanning both inpatient and outpatient care. With this current study, we add evidence regarding the program's association with reduced rehospitalization rates and demonstrate use of the CCC algorithm to construct a comparison group for analyzing the outcomes of a care coordination program. With our program currently providing services to the most clinically "at-risk" children, the next goal of the program is to stratify a new at-risk patient population with both clinical and socioeconomic factors. We hope that this would increase the benefit to patients from an expanded scope of transition care coordination services at this university-affiliated medical center. Promising directions include focusing on patients with new-onset chronic disease and patients with "social complexity" factors that limit access to care.²⁰ Building a robust program evaluation methodology into the expansion of this care coordination program would allow future work to assess patient quality and experience outcomes as well as projected cost savings to the health care system.

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