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Complex Care Program Enrollment and Change in ED and Hospital Visits from Medical Device Complications

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Abstract

Introduction: Medical device-related complications often lead to emergency department (ED) visits and hospitalizations for children with medical complexity (CMC), and pediatric complex care programs may be one way to decrease unnecessary encounters. **Methods:** A retrospective cohort study comparing ED and inpatient encounters due to device complications of 2 cohorts of CMC at a single children's hospital during 2014–2016; 99 enrolled in a complex care program and 244 in a propensity-matched comparison group. Structured chart reviews identified ED and inpatient encounters due to device complications. The outcome was a change in the frequency of these encounters from the year before to the year after enrollment in the hospital's complex care program. Program effects were estimated with weighted difference-in-differences (DiDs), comparing the change in mean encounter frequency for CMC enrolled in the program with change for propensity-matched children not enrolled in the program. **Results:** Mean encounters related to device complications decreased for both groups. Complication-related ED encounters per year decreased from a weighted mean (SD) of 0.74 (0.85) to 0.30 (0.44) in enrolled children and 0.26 (0.89) to 0.12 (0.56) in comparison children, a DiD of 0.30 fewer [95% confidence interval (CI) –0.01 to 0.60]. The largest reductions in device complication ED visits were among those with enteral tubes [0.36 fewer (95% CI 0.04–0.68)]. Hospitalizations decreased over time, but DiDs were not significantly different between groups. **Conclusions:** Acute care use from device complications decreased with time. Complex care program enrollment may be associated with more substantial reductions in device complication ED visits, and effects may be most pronounced for CMC with enteral tubes.
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INTRODUCTION

Many children with medical complexity (CMC), that is, children with progressive or severe chronic conditions, substantial needs, and health services use, are assisted by medical devices to support vital functions. Complications related to these devices, such as tracheostomy tube dislodgement or central venous catheter infections, often lead to emergency department (ED) visits and hospitalizations.[1,2] Medical device complications are among the most common reasons for hospital admission among CMC,[2–4] and many of these encounters may be preventable.[3]

Pediatric complex care programs have recently emerged,[2] aspiring to improve CMC's health outcomes by enhancing coordination, promoting patient- and family-centered care, and facilitating access to resources to meet caregiving needs.[4,5] Although pediatric complex care programs vary in size and scope, they are often clinical programs based at tertiary care centers with a multidisciplinary team including care coordination staff that address clinical care, growth, development and nutrition, and health system and community resource navigation.[4] Recent reports suggest complex care programs may lead to reductions in health services use.[6,7] How such programs might accomplish these reductions, however, is mostly unknown. One potential mechanism for reducing ED visits and hospitalizations is through the prevention of medical device complications.

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For example, dependable medical technology is considered a key driver for preventing CMC hospitalizations.[8,9] However, little empirical data exist to confirm whether complex care enrollment affects the rate of encounters related to medical device complications. Our objective was to evaluate whether enrollment in a complex care program was associated with a reduction in ED visits and hospital admissions due to medical device complications. We hypothesized that being enrolled in such a program would be associated with a decline in these encounters. These results would add to the growing evidence that complex care program enrollment reduces healthcare utilization and suggest one potential mechanism for this reduction.

METHODS

Context

This propensity-matched retrospective cohort study included children who met the criteria for enrollment in the Pediatric Complex Care Program at UW Health-American Family Children's Hospital (AFCH) between April 2014 and April 2016 and were assisted by at least 1 medical device to support an essential body function during this time period.

Intervention

The Pediatric Complex Care Program is a clinical program comprised general pediatricians, advanced practice providers, registered nurses, social workers, and care coordination assistants who provide care coordination and medical co-management for CMC. Program enrollment criteria include ≥3 body systems affected by chronic conditions, the involvement of ≥3 subspecialists, and either hospitalization for ≥5 days or ≥10 clinic visits in the prior year. CMCs are referred for enrollment by inpatient or outpatient primary and subspecialty care providers, community organizations, and families.

Enrollment into complex care typically consists of a 90-minute comprehensive visit. After this enrollment visit, planned follow-up for comprehensive care planning and care coordination includes a 60-minute visit 2 months after enrollment followed by 60-minute clinic visits 6 months after enrollment and every 6 months after that. In addition, children enrolled in the program are seen by the complex care team for urgent visits as needed and during hospital admissions to AFCH. The child's family also receives structured monthly phone calls to identify and address unmet needs between visits. Children continue to see their primary care provider and subspecialists while enrolled in the program. The complex care program provides care coordination and medical co-management while assisting with areas not covered by the child's other healthcare team members. The program is a "first call" for medical questions and provides families with tools to troubleshoot medical device complications at home. For example, the complex care team develops "enteral tube action plans" to help manage feeding tube complications at home. The team helps families contact their child's durable medical equipment company or specialists to assist with supply needs or device malfunctions.

Population

We used our electronic health record (EHR) to identify a pool of children in our health system who met our complex care program's eligibility criteria, estimating numbers of affected body systems with Feudtner's Complex Chronic Conditions.[10] From this pool of children, we further identified 2 groups: (1) children enrolled in the Pediatric Complex Care Program during the study period ("case-children") and (2) a propensity-matched comparison group who were eligible but not enrolled ("comparison-children").

To generate propensity scores, we first identified variables from our EHR data that we hypothesized motivate referral and enrollment into our program (Table 1). This list of characteristics was developed a priori through consensus discussion with the complex care team and includes demographic, geographic, primary care, medical complexity, and severity variables. Matching aimed to minimize differences between groups about factors that we hypothesized motivate referral and enrollment into complex care. Case-children and comparison-children were matched using genetic propensity matching, which applies an algorithm to iteratively check propensity scores, attempting to maximize at each step the smallest *P* value across the covariates using a combination of propensity score matching and Mahalanobis distance matching.[11] We used variable-ratio matching with replacement with a goal of 4 comparisons per case to reduce bias and improve the precision of treatment effect estimates compared to one-to-one matching.[11] This method also reduces the risk of lower-quality matches compared to fixed-ratio matching because the latter requires a minimum number of matches for each case, even if some cases may not have multiple high-quality matches.

We constructed frequency weights to account for comparison group children being in the study more than once and for cases having a variable number of comparison

Table 1. Characteristics Used in Propensity Matching

Age
Gender
Race/ethnicity
Insurance status (public, private, none)
Area and zip codes (distance from hospital clinical program)
Primary care provider specialty
No. complex chronic conditions
Specific body systems involved (presence or absence of each complex chronic condition)
Technology assistance (determined by complex chronic condition algorithm)
Hospital use in year before enrollment
Clinic visits in year before enrollment

To generate propensity scores, variables available in the EHR and hypothesized to motivate referral and enrollment into the AFCH Pediatric Complex Care Program were identified a priori through consensus discussion with AFCH Pediatric Complex Care Program team.

children.[12] To further identify case and comparison children with medical devices, we adapted the definition from Feudtner's definition of technology dependence as requiring "some form of medical technology, including medications or devices; and they would if the technology were to fail or its use be discontinued, likely suffer a sufficiently adverse health consequence that hospitalization would be required."[13] We included 15 possible medical devices for this study (Table 2). We used the complex chronic conditions technology assistance indicator during propensity matching and then manually reviewed charts of case and comparison group children to include only those having at least 1 of these 15 medical devices upon study enrollment.

Definitions of Key Variables

Device Complication ED Visits and HOSPITALIZATIONS

We defined ED visits as any ED visit for which a health care provider recorded a history and physical note, regardless of the child's disposition. The team defined hospitalizations as any inpatient or observation hospital stay with a discharge summary. All patients' ED and hospital visits were included during the study time frame. Visits likely related to device complications were identified using a method previously described.[1] Three reviewers (a trained research assistant and two physician reviewers, each with over 10 years of complex care experience) established high interrater reliability (Kappa = 0.92).

Study of the Intervention

The team abstracted variables used for establishing program eligibility and propensity matching from the EHR. We defined complex care case-children enrollment date as the day of their first healthcare visit with the complex care team. For comparison-children, a "pseudoenrollment" date was identified to account for the time elapsed between meeting complex care program criteria, being referred, and being enrolled in the program. We used the case group's median time from first meeting program criteria to enrollment, which was 385 days. Data on medical devices and device complication visits in the year before and after enrollment or pseudoenrollment were collected by manual EHR review. Reviewers had access to all aspects of the EHR, including the history and physical, progress, transfer, ED, discharge summary notes, laboratory data, and outpatient encounters. Although available data were primarily limited to data within our health system, we attempted to identify any device complication visits outside of our healthcare system using the Care Everywhere feature in the Epic EHR (Epic System Corp, Verona, Wis.). We entered study data into a Research Electronic Data Capture (REDCap) database.[14]

Table 2. Fifteen Medical Devices Included in Analyses

CPAP/BiPAP
Tracheostomy without ventilator
Tracheostomy with ventilator
Insulin pump
Home oxygen
Ventricular shunt
Central venous catheter
G-tube
GJ- or J-tube
NG or NJ tube
Baclofen pump
Pacemaker
Dialysis
Vagal nerve stimulator
Ileostomy/colostomy

BiPAP, bilevel positive airway pressure; CPAP, continuous positive airway pressure; G-tube, gastrostomy tube; GJ, gastrostomy-jejunostomy; j-tube, jejunostomy tube; NG, nasogastric; NJ tube, nasojejunal tube.

Analysis

Descriptive statistics summarized characteristics of the case and comparison groups and assessed for statistically significant differences in matching characteristics using chi-squared tests for differences in proportions and t-tests or Wilcoxon rank-sum tests for continuous variables. Paired t-tests evaluated differences in mean ED visits and hospitalizations from device complications 1-year prior and 1-year post complex care enrollment.

Weighted difference-in-difference (DiD) estimates were calculated to compare the changes in device complication ED visits and hospitalizations for case-children with the changes in the propensity-matched comparison-children. Finally, we conducted preplanned secondary analyses looking at weighted DiD estimates for each of the 15 distinct medical devices separately. Propensity matching was accomplished using the MatchIt package in R,[15,16] and all additional analyses were performed in STATA (SE version 15, College Station, Tex.). The Institutional Review Board of the University of Wisconsin-Madison approved this study.

RESULTS

A total of 2,254 eligible CMC were identified, 170 children enrolled in complex care and 2,084 who were not. Propensity matching resulted in n = 170 from complex care matched to n = 680 comparisons (n = 426 unique individuals, Fig. 1). After manually screening all children for medical devices as defined in this study, our final cohort included 99 cases and 467 comparisons (among n = 244 unique comparison-children). Although the baseline rate of ED visits and hospitalizations for medical device complications differed between the 2 groups, there were no other significant weighted demographic, geographic, or clinical differences between the 2 groups (Table 3). Both had similar degrees of medical complexity as well as numbers and types of medical devices. Gastrostomy and gastrojejunostomy tubes were the most common medical devices, with 94% and 82% of patients in complex care case and comparison groups having these devices, respectively. Preenrollment healthcare utilization was similar between both groups, including the numbers

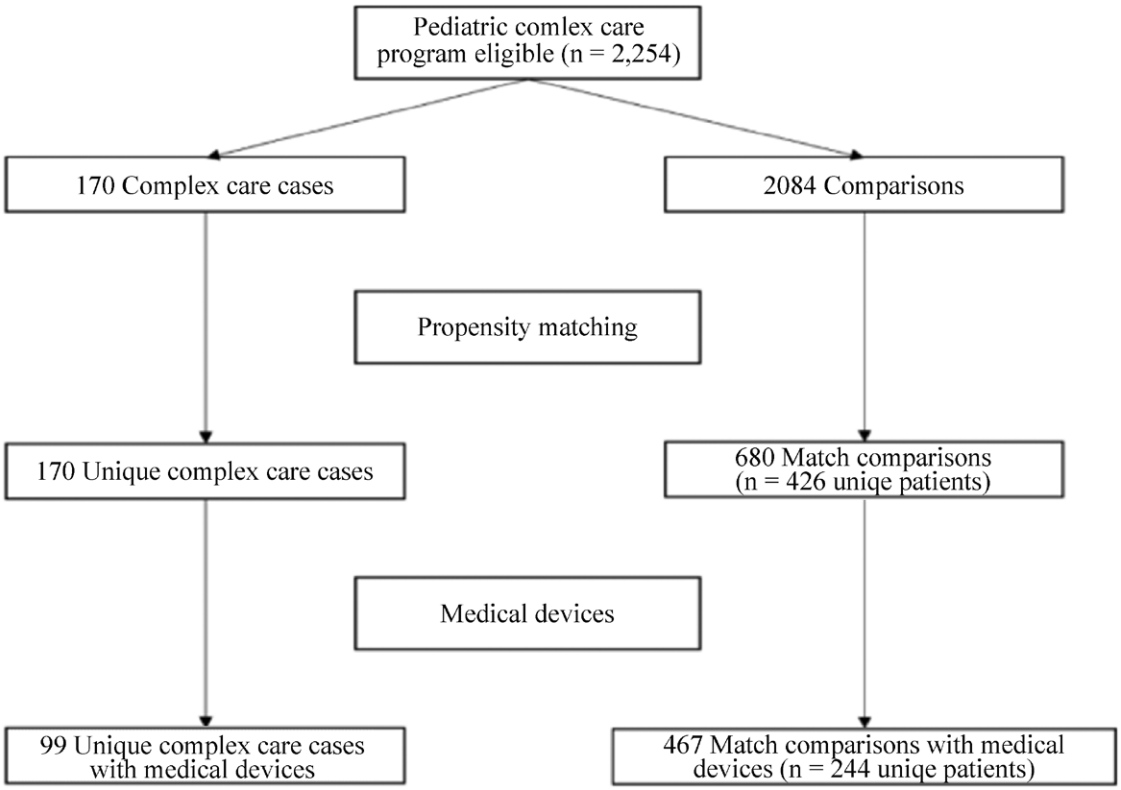

Fig. 1. Study flow diagram.

of subspecialists, ambulatory visits, and hospital days in the year before enrollment or pseudoenrollment.

Device Complication ED visits

In the complex care case-children, the weighted mean of 0.74 device complication ED visits per patient in the year before enrollment decreased to 0.30 in the year after enrollment (P = 0.001). In the propensity-matched comparison-children, the weighted mean of 0.26 such visits per patient in the year before pseudoenrollment decreased to a mean of 0.12 device complication ED visits per patient in the year after pseudoenrollment (P = 0.04). In weighted DiD analyses, the change in device complication ED visits was reduced in the case-children group more than the comparison-children, but this difference failed to reach statistical significance (DiD 0.30 [95% confidence interval (CI): −0.01 to 0.60], P = 0.06) (Fig. 2A).

Device Complication Hospitalizations

In the complex care case-children, the weighted mean of 0.55 device complication hospitalizations per patient in the year before enrollment decreased to a mean of 0.36 in the year after (P = 0.03). In the propensity-matched comparison-children, the mean of 0.26 hospitalizations in the year before pseudoenrollment decreased to 0.18 in the year after (P = 0.39). In weighted DiD estimates, the change in device complication hospitalizations was not significantly reduced for the case-children beyond the comparison-children (DiD 0.09 [95% CI: −0.16 to 0.35], P = 0.47) (Fig. 2B).

Device-specific Secondary Analysis

In the preplanned secondary analyses of the 15 different medical devices, the largest absolute reduction in device complication ED visits was for children with enteral tubes (ie, gastrostomy, gastrojejunostomy, or jejunostomy tubes). Device complication ED visits were reduced for case-children relative to the comparison-children (weighted DiD 0.36 [95% CI: 0.04–0.68], P = 0.03) (Fig. 2C). The medical device associated with the second largest absolute reduction in device complication ED visits was tracheostomy, though the DiD was not statistically significant (Table 4).

DISCUSSION

ED and hospital visits from device complications decreased for CMC over the study period. Enrollment in complex care may be associated with reductions in device complication ED visits beyond that which otherwise occurred. These findings were particularly concentrated among children with gastrostomy, gastrojejunostomy, or jejunostomy tubes. Although a few studies have shown that complex care programs are associated with reductions in ED use and hospitalizations,[3,7,17] the specific

Table 3. Weighted Clinical and Demographic Characteristics of Complex Care and Propensity-matched Comparison Groups

	Complex Care Case Group* (n = 99)	Propensity-matched Comparison Group* (n = 467†)
Complex chronic conditions, median (IQR)	5 (4–6)	5 (4–6)
No. devices, median (IQR)	2 (1–2)	1 (1–2)
Most common medical devices, %		
Gastrostomy or GJ-tube	94	92
Tracheostomy	14	12
Ventricular shunt	13	15
Healthcare utilization (past year)		
Subspecialists involved, median (IQR)	3 (3–6)	3 (3–5)
Ambulatory visits, median (IQR)	14 (10–28)	14 (10–24)
Hospital days, mean (SD)	10.3 (21.7)	6.9 (14.5)
Age, y, median (IQR)	5 (1–11)	5 (2–9)
Gender, female, %	45	45
Race/ethnicity, %		
White, non-Hispanic	80	88
Black, non-Hispanic	12	6
Hispanic, any race	8	6
English primary language, %	97	97
Local area code, %	64	62
Wisconsin resident, %	81	80
No passive smoke exposure, %	79	76
Primary Payer, %		
Public	40	43
Commercial	50	50
Primary care is general pediatrician, %	73	80

*No statistically significant differences between the 2 groups was observed.
†Value represents number of comparisons (from 244 unique individuals) used to match to the 99 children in case group.
GJ, gastrojejunostomy.

mechanisms through which complex care may exert this influence have been less clear. Our findings suggest that enrollment in complex care might specifically influence healthcare utilization for medical device complications. The reductions observed over time for enrolled and non-enrolled CMC highlight the challenge of interpreting uncontrolled prepost analyses.

There are likely several reasons that device complication visits decrease over time for most patients, whether enrolled in complex care or not. First, we suspect that families develop confidence in caring for their children's medical devices over time, which may influence how and when they seek acute care.[8,18] Second, they may become more skilled at troubleshooting technical aspects of devices at home. Developing a broader set of troubleshooting options to address problems before they become crises might mitigate the need for healthcare provider intervention. Similarly, the child's family may become more adept at navigating the health care system, accessing outpatient resources to help manage their child at home or in a non-ED clinic visit. Third, the child's health may simply stabilize from 1 year to the next.[19] Problems with devices may be less serious the longer the child has the device (eg, a mature gastrostomy stoma facilitates tube replacement at home instead of the ED).

Although reductions in CMC healthcare utilization may occur naturally over time, focused interventions from clinical programs could conceivably yield additional reductions. The theory that complex care can prevent device complication-related utilization has growing research support. For example, a modified-Delphi expert panel on CMC hospital use concluded that reliable device use and proficient users were key drivers for interventions to lower overall hospitalizations.[3] Device complications appear to comprise a sizable proportion of overall ED and hospital use for CMC, with one previous study suggesting as much as 17% of total hospitalizations for CMC with medical devices were due to device complications in the year before enrollment in a complex care program.[1] One of the only other studies to quantify the proportion of hospitalizations attributed to medical device complications observed that 9% of hospitalizations for CMC were due to medical device complications[2]; however, those children were already enrolled in a complex care program.

We hypothesize that parent shared management,[20,21] moderated by well-designed health system support,[18] could drive reductions in acute care utilization over time. Whether interventions can accelerate and enhance these relationships is not yet known, though is plausible. For example, a large multisite learning collaborative recently used statistical process control and propensity matching to demonstrate reductions in hospitalization and cost with enrollment in complex care programs.[22] The Plans for Action and Care Transitions intervention, focusing on CMC caregiver coaching and skill-building, demonstrated reductions in hospital use.[23] This work was consistent with a study by Graham et al,[17] who observed that a critical care-based care coordination model for CMC with respiratory failure was associated with reductions in ED visits and hospitalizations. Although these studies were not designed to look at the effects of device complications or

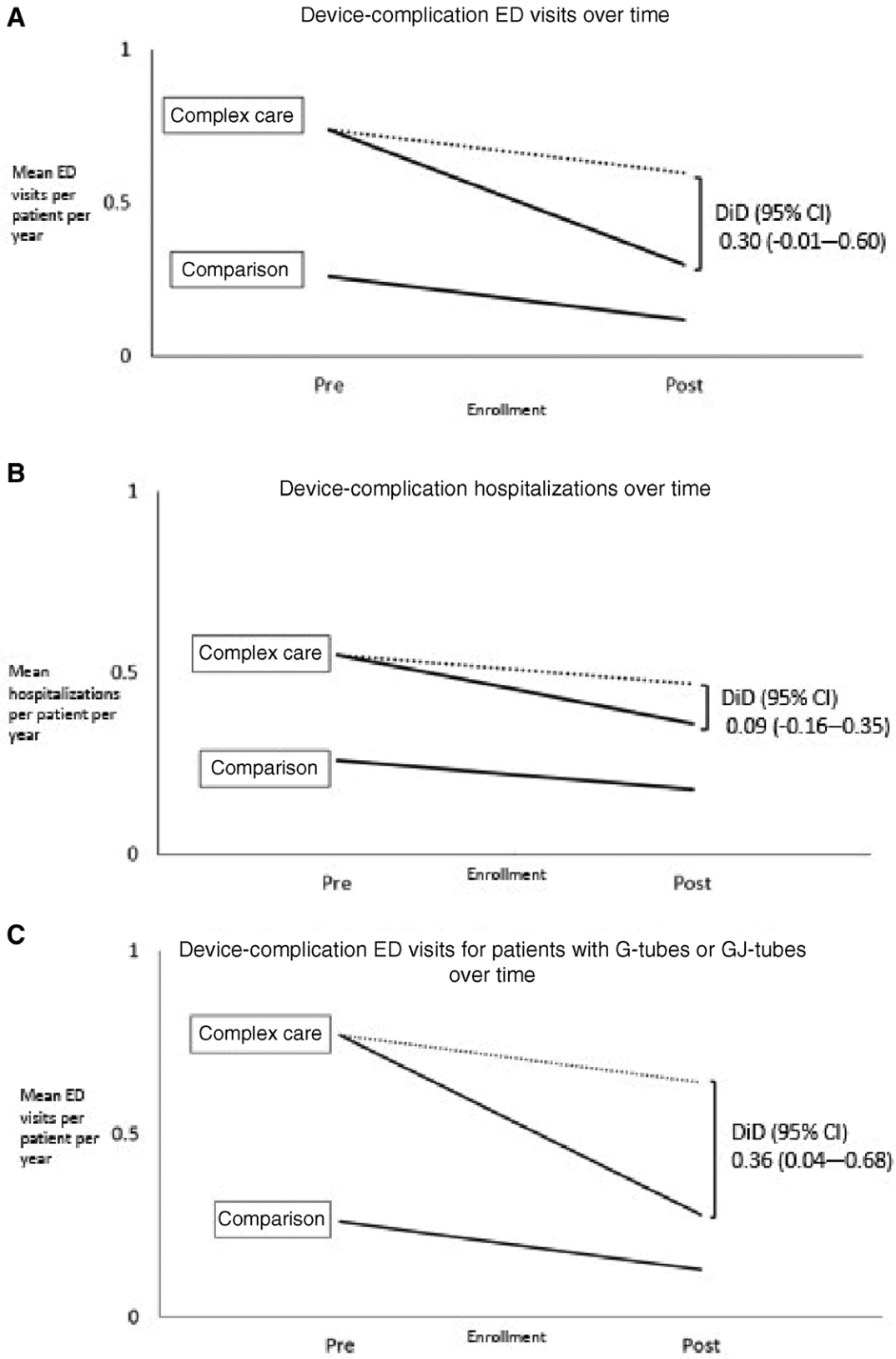

Fig. 2. Weighted DiD device complications. Acute visits for children following enrollment in complex care and propensity-matched comparison group. A, ED visits. B, Hospitalizations. C, Enteral tube-related ED visits. Pre = 1 year before enrollment or pseudoenrollment; Post = 1 year after enrollment or pseudoenrollment. Shown are the 1-year DiD estimates for CMC assisted by devices who were either enrolled in complex care or in a propensity-matched comparison group. The dotted line represents the change expected in the complex care group if it were to have changed at a rate similar to the comparison group.

Table 4. Weighted DiD Device Complication Encounters for Children Following Enrollment in Complex Care and a Propensity-matched Comparison Group, Overall and for Selected Devices

	Complex Care		Comparison		
	Pre	Post	Pre	Post	Net Reduction DiD (95% CI)
ED, mean visits/patient/y (SD)					
Overall	0.74 (0.85)	0.30 (0.44)	0.26 (0.89)	0.12 (0.56)	0.30 (–0.01 to 0.60)
Children with enteral tubes	0.77 (0.89)	0.27 (0.38)	0.26 (0.90)	0.13 (0.57)	0.36 (0.04 to 0.68)
Children with tracheostomies	0.50 (0.55)	0.29 (0.43)	0.30 (0.76)	0.19 (0.63)	0.10 (–0.55 to 0.74)
Hospitalization, mean visits/patient/y (SD)					
Overall	0.55 (0.61)	0.36 (0.47)	0.26 (0.79)	0.18 (0.66)	0.09 (–0.16 to 0.35)
Children with enteral tubes	0.55 (0.10)	0.40 (0.49)	0.26 (0.08)	0.19 (0.68)	0.08 (–0.19 to 0.36)
Children with tracheostomies	1.14 (0.56)	0.93 (0.63)	0.62 (1.05)	0.43 (0.75)	0.02 (–0.76 to 0.80)

Pre, 1 year before enrollment or pseudoenrollment.
Post, 1 year after enrollment or pseudoenrollment.

caregiver shared management explicitly; future well-powered prospective studies could answer these questions and advance this line of research. If confirmed, ED visits and hospitalizations due to medical device complications may become a useful outcome measure to assess complex care program effectiveness.

It was also notable that reductions in device complication healthcare encounters for CMC enrolled in our program appeared most pronounced in the children with enteral tubes. Acute care use for enteral tube complications can be precipitated by many problems, including peristomal issues (granulation tissue and cellulitis) and tube problems (poorly fitted or dislodged tubes, obstructions, device breakage, and other mechanical problems), among others. A recent national study demonstrated that in the month following tube placement, almost 10% of children had gastrostomy tube-related ED visits with 4% requiring hospital admission; however, this study was not limited to CMC.[24] Lack of evidence- or consensus-based standards for general enteral tube care, such as materials, sizing, cleansing, flushing, stoma management, and troubleshooting approaches, leads to variation within and across institutions and may also drive complications.[25]

Complex care programs could reduce device complication ED visits through a variety of means, especially for children with enteral tubes. Care standardization may be a pivotal driver to decrease acute enteral tube-driven utilization. For example, a recent retrospective cohort study observed lower hospital resource utilization following G- or GJ-tube placement after implementing a clinical pathway compared to a historical cohort.[26] Most complex care programs, including ours, support access to a knowledgeable provider, proactive care and crisis planning for devices, and educational reinforcement about medical devices, particularly enteral tubes. Programs often facilitate communication across relevant specialties when needed, including pediatric gastroenterology, surgery, and interventional radiology. Focusing attention on the development of consensus standards and interventions to prevent enteral tube complication visits might be a promising next step for CMC researchers and clinicians.

An unexpected but important finding, as well as study limitation, was that despite our data suggesting the propensity matching successfully balanced important confounders, the comparison-children had lower baseline rates of encounters for medical device complications than the complex care case-children. Although we tried to make the relevant characteristics of our case- and comparison-children as similar as possible using a priori conceptually-grounded variables in the propensity matching, important covariates were likely excluded. Little is actually known about the determinants of complex care program referral, uptake, and retention. A meaningful secondary finding from our study is that a history of recent device complications could be an important motivating factor for referral and subsequent enrollment into complex care. We will explore this with a planned qualitative study to better understand what motivates parents and providers to refer, enroll, and remain in complex care.

This study has other important limitations. As a retrospective observational study, causal relationships between complex care enrollment and the study outcomes cannot be determined. Generalizability and power were limited by the single-center design and relatively small sample size. Furthermore, although we tried to capture all ED visits and hospitalizations both within and outside our system by utilizing the Care Everywhere feature in the Epic EHR, some encounters were potentially missed, particularly in the nonenrolled comparison group. Although our data suggest that the device complication visit metric is reliable, its validity is not formally established.

CONCLUSIONS

Despite these limitations, this study is one of a few to examine how complex care programs may reduce CMC health services use. It is among the first to examine the potential impact of enrollment in a complex care program on ED visits and hospitalizations due to medical device complications. The results of this study suggest that complex care may be associated with fewer medical device complication ED visits for CMC, particularly those with enteral tubes. This study demonstrates that ED visits and hospitalizations due to medical device complications are

outcomes that can be measured and tracked. Complex care and related clinical teams can extend this work to examine the effect of interventions to support medical device use on ED visits and hospitalizations. Moreover, whether associated with acute care use or not, all medical device complications are potentially valuable for clinical programs to monitor prospectively while implementing continuous quality improvement and rapid tests of change. For example, implementing anticipatory guidance scripts for common devices, standardizing device surveillance approaches during well visits, using action plans for families to detect and troubleshoot device problems early, and developing new parent/family educational approaches such as simulation or peer support, are potential starting points. There is a sizable opportunity for clinician and family partnership to develop and test additional novel strategies to improve child health.

DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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