

# A Multidisciplinary Home Visiting Program for Children With Medical Complexity

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## ABSTRACT

**OBJECTIVES:** Given the high needs and costs associated with the care of children with medical complexity (CMC), innovative models of care are needed. Home-visiting care models are effective in subpopulations of pediatrics and medically complex adults, but there is no literature on this model for CMC. We describe the development and outcomes of a multidisciplinary program that provides comprehensive home-based primary care for CMC.

**METHODS:** Medical records from our institution were reviewed for patients enrolled in our program from July 2013 through March 2019. Demographics, clinical characteristics, and health care use were collected. We compared the differences in pre- and postprogram enrollment health care use using Wilcoxon signed rank test. We applied Cox proportional hazard models to examine the association between the time-dependent postenrollment health care use and numbers of home visits. We collected total claims data for a subset of our patients to examine total costs of care.

**RESULTS:** We reviewed data collected from 121 patients. With our findings, we demonstrate that enrollment in our program is associated with reductions in average length of stay. More home visits were associated with decreased emergency department visits and hospitalizations. We also observed in patients with available cost data that total costs of care decreased after enrollment into the program.

**CONCLUSIONS:** Our model has the potential to improve health outcomes and be financially sustainable by providing home-based primary care to CMC.



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Children with medical complexity (CMC) have intensive care needs that are often not addressed under our current care models.<sup>1</sup> CMC are defined as those with significant chronic medical conditions that often affect multiple organ systems. Representing a distinct subset of children with special health care needs, CMC frequently have severe functional limitations, rely on medical technology and have high health care use and costs.<sup>2</sup> Families of CMC face significant challenges in accessing high quality care and navigating our complex health care system.<sup>3,4</sup> When compared with children who are less medically complex, children with greater complexity experience higher care burden and unmet medical needs.<sup>5</sup> Families are too often left to manage complicated medical care plans and medication regimens outside of the hospital setting with few resources and supports.<sup>5</sup>

Despite the growth of this complex population, there are relatively few studies in which effective and sustainable models of care for CMC are demonstrated. Researchers around the broader category of children with special health care needs clearly cite the need for strong medical homes and care coordination to help address challenges.<sup>6-9</sup> Although new models of care have emerged for CMC over the last few decades to address these issues, there continue to be many gaps in care, including poor integration of medical and community services, limited focus on mental and behavioral health, difficulty with transition to adult care, and inadequate support to caregivers.<sup>10</sup>

Home-based care has become a focus in adults with complex chronic conditions, but within pediatrics, home visitation has only been studied in children with asthma and newborns<sup>11-15</sup> Currently, there is no literature on physician-led multidisciplinary home visits for CMC. Our institution has one of the oldest and largest academic home visiting programs for adults in the country.<sup>15</sup> An exemplar model of home-based care, the program serves >1200 adult patients annually and provides care through a multidisciplinary team including physicians, nurse practitioners, nurses, social workers, and administrative staff. Outcomes of this

program include decreases in annual hospitalization rates, fewer 30-day readmissions, reduced physician burnout, and positive financial contributions to the health system resulting in the growth and sustainability of the program.<sup>16,17</sup>

On the basis of the success of our adult counterpart program and growing evidence that care through medical homes with enhanced care coordination can address unmet needs, we created a home-based primary care program in pediatrics.

The program has evolved to focus predominantly on CMC and to provide both home and office-based care through a multidisciplinary team. In this article, we describe the development, structure, and outcomes of our program.

## METHODS

### Setting

The Pediatric Visiting Doctors and Complex Care Program is part of a general pediatrics clinic in a large tertiary academic hospital located in an urban setting. The clinic provides >20 000 visits and serves nearly 9000 unique patients annually, is the teaching site for ~60 pediatric residents, and is the practice site for 15 attending-level pediatricians. The clinic's population is 87% Medicaid covered and primarily low-income. Families are often psychosocially complex and experience barriers limiting their ability to access high quality health care. Such barriers include cost of transportation, caregivers' inability to miss work, lack of child care for other children, mistrust of the health care system, language and cultural barriers, immigration status, and caregivers' physical and/or mental health.

### Program Design and Evolution

The program was started in July 2013 under a Patient-Centered Medical Home demonstration project awarded by our state. Initially, the program provided home visits to children with poorly controlled asthma, high-risk newborns, and CMC. Physician and social work teams conducted home visits within an area of ≤3 miles away from the hospital. In July 2015, because of the increasing number of CMC referred who lived outside the catchment

area, we started the complex care clinic of the program within the physical space of our general pediatrics clinic to access the same multidisciplinary team. CMC in that arm receive most of their care within the clinic, with occasional home visits to perform home and safety assessments when indicated. The care provided follows the program model including extended appointment times, multidisciplinary support, and coordination with subspecialty appointments when possible.

During the initial 3 years of program funding via the state grant, we worked closely with our department and our system's population health program to collect use and outcomes data for our patients. The estimated cost-savings, detailed below, with our full-risk population exceeded the operating costs of the program, making us financially sustainable. The hospital has since funded the program as a unique model of care for CMC important to the hospital's approach to population health.

### Current Team and Roles

The team currently consists of two pediatricians, one medicine-pediatrics trained physician, one nurse clinical coordinator, three social workers (two of which are shared with our pediatric clinic), two care coordinators and two part-time administrative assistants. The physicians represent 1.7 full-time equivalents in the program and see patients at home ~3 to 4 days per week. The physicians provide outpatient care and manage patients when admitted to the hospital but do not have a primary inpatient service. The nurse clinical coordinator triages patient phone calls, rounds with inpatient teams when program patients are admitted within the hospital, reviews all orders and forms, and coordinates with pharmacies, schools and members within the team. The social workers perform comprehensive psychosocial assessments and provide ongoing support to families including referrals to community-based organizations, educational advocacy, and supportive counseling. The care coordinators assist in scheduling appointments, arranging transportation, and coordinating with

subspecialists and pharmacies and address other social determinants of health. The administrative assistants provide administrative support to the program including budget management, insurance referrals and previous authorizations, and telephone support.

### Services Offered

In addition to the care coordination above, the program provides primary medical care. For patients in the catchment area, they receive both primary and urgent medical care at home. The team has access to perform radiographs and phlebotomy and obtain laboratory specimens (respiratory cultures, polymerase chain reaction swabs, etc) at home. The social workers and/or care coordinators attend all initial home visits with the physicians to conduct a psychosocial evaluation and home assessment. Telehealth is also available to all patients as of July 2019.

### Patient Populations

The clinical criteria for admission into the program have evolved since its inception. At the start of the program, a broader net of patients was included to be able to conduct as many home visits as possible and better understand the resources and needs within the community. With time, the focus has become on providing care to CMC and newborns who are at high risk to become CMC.

### High-Risk Newborns

Infants discharged from the NICU at our institution are enrolled on the basis of gestational age (<30 weeks) and medical and psychosocial complexity. The NICU team identifies patients to refer for primary care. The patients are seen at minimum based on the standard well child schedule, often more if clinically indicated. After 6 to 9 months of being managed at home or in the clinic, those infants with perinatal conditions that have resolved and/or are being adequately managed with decreased care burden are transitioned to the general pediatrics clinic for their primary care.

### CMC

CMC are referred to the program by primary care providers, inpatient providers,

and subspecialists to receive multidisciplinary comprehensive primary care. Children qualify if they have two or more complex chronic conditions (excluding asthma, obesity or behavioral and psychiatric conditions), one major medical problem that involves multiple organ systems, or an immediate palliative care need (new diagnoses, significant deterioration, hospice referral) or are technology dependent (feeding tube, respiratory support, wheelchair bound, etc). The physicians provide primary care in the home if the patients live within the catchment area; otherwise, they are seen in the office. Medical care at home and in the clinic includes routine examinations, urgent sick visits, vaccinations, and coordination with subspecialists. The visits occur alongside the social worker and/or care coordinator to identify and address the families' psychosocial needs. The patients are seen at least every 3 months depending on their clinical status.

### Data Collection and Analysis

We reviewed the electronic medical records at our institution of all CMC enrolled in our program from July 2013 through March 2019. Patients included in the analysis were enrolled in any arm of the program for  $\geq 3$  months and had  $\geq 1$  encounter with our team. Electronic medical record data collected included demographics, medical technology use, insurance, and service use (office and home visits, emergency department [ED] visits, and hospitalizations).

Pre- and postenrollment hospital use data were collected including ED visits and hospitalizations at our institution. Hospitalizations were categorized as planned or unplanned based on reason for admission (ie, a scheduled surgery such as gastrostomy tube placement was considered planned, whereas a gastrostomy/jejunostomy tube that dislodged was considered unplanned). We compared hospital use pre- and postenrollment, looking at equivalent time periods from enrollment date for CMC. If a patient was discharged from the program (because of death, change in care, move, or lost to follow-up), the time period to discharge was

used for the analysis. If a child's pre-enrollment time period coincided with birth, then an equal postenrollment time period was used (ie, if a patient was 2 years old at the time of enrollment and had been enrolled for 3 years, only 2 years of data were assessed both pre- and postenrollment). Birth admissions were excluded from the analysis because they were not considered potentially controllable use. The use was adjusted for enrollment time by dividing the number of events by the enrollment time in months.

A subset of our CMC population is insured through full-risk models with our hospital system. We have access to total claims data for that population and are able to trend their costs of care. On the basis of data extracted in July 2019 for claims data up through March 2019, we compared the total costs of care for enrolled members one year previously, the first year during, and the second year during enrollment to our program.

We summarized the characteristics of patients and their health care use using frequency and proportions for categorical variables, reported mean (SD), and median (interquartile range [IQR]) for continuous

**TABLE 1** Patient Characteristics

	<i>N</i> = 121; <i>n</i> (%)
Sex, male	66 (55)
Race	
White	9 (7)
African American	32 (26)
Asian American	5 (4)
American Indian	1 (1)
Other Pacific Islander	1 (1)
Other	71 (59)
Unknown	2 (2)
Ethnicity	
Hispanic	57 (47)
Non-Hispanic	54 (45)
Unknown	10 (8)
Language	
English	77 (64)
Spanish	32 (26)
Other	12 (10)
Public insurance as primary, yes	109 (90)

variables. We used Wilcoxon signed rank test to compare the pre- and postenrollment differences in the five continuous health care use outcomes adjusted for enrollment time: ED visits, total and unplanned hospitalizations, length of stay (LOS) for total and unplanned hospitalizations, and 30 day readmission rate. The correlation among these continuous uses, and home visit, clinic visit, and enrollment time were examined using Spearman rank-ordered correlation and presented as supplemental information (Supplemental Fig 3). On the basis of whether participants had any (versus none) specific health care use events during the postenrollment period, we dichotomized health care use outcomes (eg, ED visits: yes versus no, hospitalizations: yes versus no, 30-day readmissions: yes versus no) and considered the use event to have occurred at the end of the enrollment. We dichotomized LOS using median values from those who had hospitalizations, which were 5 and 7 days for all and unplanned hospitalizations, respectively. We applied Cox proportional hazard models to examine the association between home visit and each of these dichotomized outcomes, respectively, while adjusting for clinic visits and corresponding pre-enrollment health care use. As a sensitivity analysis, we also used the 25th and 75th percentile to dichotomize LOS; the results were similar to the main findings using the median (data not shown). All tests were 2-sided, and  $P$  value  $<.05$  was considered statistically significant. The analysis was conducted in SAS V9.4 (SAS Institute, Inc, Cary, NC).

## RESULTS

From July 2013 through March 2019, we enrolled 265 patients into the program. Of those, 121 were enrolled as CMC and 99 as high-risk newborns. An overview and analysis of our newborn population was previously published, and thus, we will focus only on results of CMC in this article.<sup>18</sup>

For the CMC population, we have enrolled 121 patients into the program. As of April 2019, we conducted 622 home visits and 865 visits in the office with patients in our

**TABLE 2** Characteristics of Patient Enrollment Information and Health Care Use

	Mean (SD)	Median (IQR)
Age at enrollment, y	6.8 (6.2)	5.0 (1.2–11.9)
Age at assessment or discharge, y	8.7 (6.4)	7.2 (2.9–14.1)
Months enrolled	21.5 (17.3)	14.2 (9.1–31)
Home visits	5.3 (10.1)	0 (0–7)
Clinic visits	7.1 (6.4)	5 (3–10)
Home and clinic visits	12.4 (10.5)	10 (5–16)

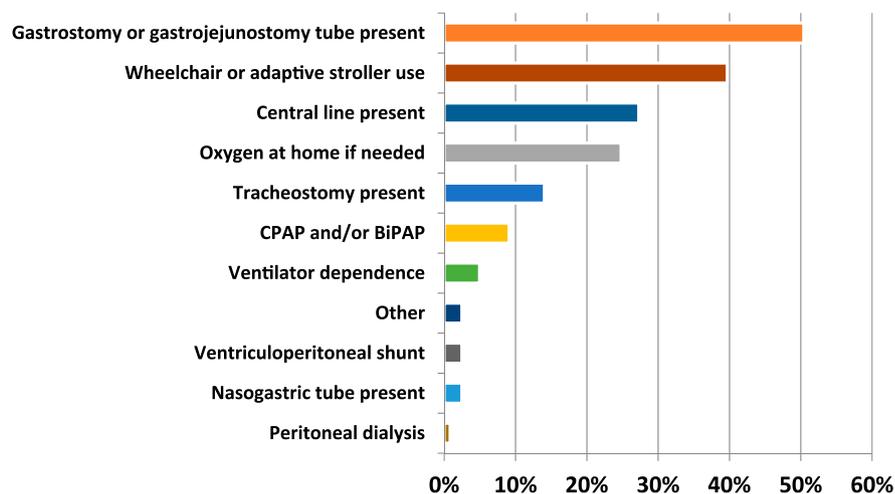
program; thus, 42% of our encounters have been in the home. As seen in Table 1, the majority of patients are male (55%). The population is racially diverse, with the majority of patients identifying as people of color. The majority of families also identified as Hispanic (47%). Almost 40% of the patients report they prefer to communicate in a language other than English. The vast majority of patients have public insurance as their primary coverage (90%). The median age at enrollment was 5.0 years. The median enrollment time for the analyzed patients was 14.2 months (Table 2). In terms of technology dependence, about half of the patients in the program have a feeding tube, and 40% rely on a wheelchair for ambulation as seen in Fig 1.

We found statistically significant differences between pre- and postenrollment LOS for both all ( $P = .0439$ ) and unplanned hospitalizations ( $P = .0406$ , Fig 2), which decreased after enrollment into the

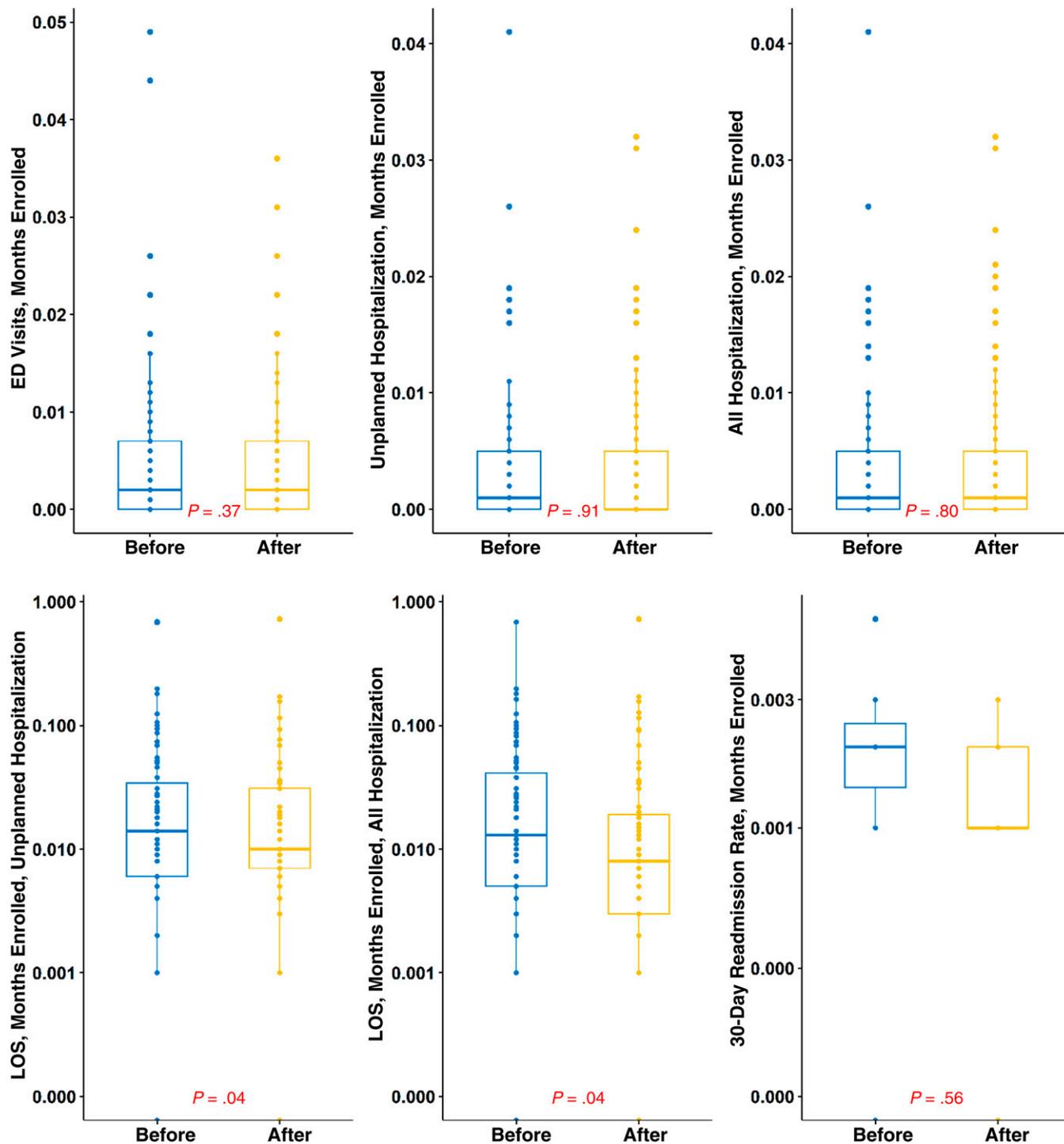
program. All other changes in pre- and post-health care use were not significant.

The Cox regression models showed that increased home visit was associated with decreased risk of postenrollment health care use (Table 3). The association was statistically significant for ED visits (hazard ratio [HR] = 0.936, 95% confidence interval [CI]: 0.902–0.972,  $P = .0005$ ), all hospitalizations (HR = 0.948, 95% CI: 0.913–0.984,  $P = .0055$ ), and unplanned hospitalizations (HR = 0.960, 95% CI: 0.920–0.998,  $P = .0388$ ) but not significant for LOS or 30-day readmission rate.

On the basis of the available claims data for the subset of patients which are our full-risk population, we observed a decrease in total spending per member per month from \$19 581 ( $n = 50$ ) to \$12 621 ( $n = 66$ ) to \$10 013 ( $n = 46$ ). The majority of the reductions in total cost of care are due to reductions in inpatient costs.



**FIGURE 1** Distribution of technology use among the CMC population ( $N = 121$ ). BiPAP, bilevel positive airway pressure; CPAP, continuous positive airway pressure.



**FIGURE 2** Comparisons between pre- and postenrollment healthcare use for ED visits; unplanned and all hospitalization, respectively; LOS (days) for unplanned and all hospitalization, respectively; and 30-day readmission rate. The use was adjusted for enrollment time, by dividing the number of events by the enrollment time in months. The box plots show the mean (the line in the box), IQR (the length of the box), range of  $>1.5 \times$  IQR (whiskers), and individual data points. The  $P$  values were from Wilcoxon signed rank test for the pre- and postenrollment paired data. The y-axes for LOS and 30-day readmission rate were log<sub>10</sub> transformed for better presentation.

**TABLE 3** Associations Between Postenrollment Health Care Use Events and Home Visits ( $N = 121$ )

Outcome and Variable	Pre-enrollment Event, $n$	Postenrollment Event, $n$	Hazard Ratio (95% CI)	$P$
ED visits				
No, visits = 0	45	49	Reference	—
Yes, visits $\geq 1$	76	72	0.936 (0.902–0.972)	.0005
All hospitalizations				
No, Hospitalization = 0	54	56	Reference	—
Yes, Hospitalization $\geq 1$	67	65	0.948 (0.913–0.984)	.0055
Unplanned hospitalizations				
No, Hospitalization = 0	60	71	Reference	—
Yes, Hospitalization $\geq 1$	61	50	0.960 (0.923–0.998)	.0388
LOS for all hospitalization				
No, LOS $\leq 5$ d	81	98	Reference	—
Yes, LOS $> 5$ d	40	23	0.986 (0.946–1.028)	.5044
LOS for unplanned hospitalization				
No, LOS $\leq 7$ d	88	105	Reference	—
Yes, LOS $> 7$ d	33	16	1.002 (0.963–1.043)	.9046
30-d readmission rate				
No, rate = 0	107	104	Reference	—
Yes, rate $> 0$	14	17	0.989 (0.937–1.042)	.6691

We applied Cox hazard models to examine the association between postenrollment health care use (outcome variable) and numbers of home visits (exposure variable) using enrollment time (in months) as the time variable. The model adjusted for clinic visits and the corresponding pre-enrollment health care use (eg, when the outcome was the dichotomized [yes versus no] postenrollment ED visits, we also adjusted the total number of pre-enrollment ED visits in the model). We dichotomized LOS using the median value from those who had hospitalizations, which were 5 and 7 d for all and unplanned hospitalizations, respectively. Separate models were used for individual healthcare use events. CI, confidence interval.

## DISCUSSION

Through the creation of a novel home visiting program for CMC, we demonstrated reductions in health care use driven by reduced average LOS and financial sustainability due to reductions in total cost of care. Chart review data reveal significant reductions in average lengths of stay in the hospital. This observation may be because of our collaboration with inpatient and subspecialty providers. Such collaboration typically begins before the patient is admitted to the hospital and continues until after discharge, facilitating communication with inpatient teams, home nursing, community resources, and families to ensure appropriate and safe transitions of care into and out of the hospital.

Although care transitions are a focus for all patients in our program, our data reveal that having a greater number of home visits was associated with a decreased probability

of some health care use metrics (ED visits and hospitalizations). As suggested by these data, the home visit aspect of our program may be a critical factor in our observed outcomes. The visualization of the living situation, medications, equipment and technology, and the psychosocial dynamics are integral to understanding the families' challenges and barriers to optimal care. By being in the home, we can interact with other home-based service providers, such as home nursing, therapists, and equipment vendors. Further research is needed to identify which aspects of the program are most responsible for our observed outcomes.

Our analysis has several limitations. Our small sample size may have limited our ability to observe some differences in outcomes. The impact of the program on LOS is limited by the small sample size because we were not able to control for certain confounders, such as reason for

admission or severity of illness. The small sample size also precluded us from further stratifying our CMC population by diagnosis type. As our population grows, examining patterns of care use among CMC with similar diagnoses may provide further insight into which comorbidities may be most positively impacted by receiving care at home. Our use data were limited to our own institution. However, our population receives the vast majority of care at our hospital, and the total cost of care data mirrors the observed trends in use. We treated children who had 1 use or multiple uses as having had a use event that occurred at the end of the enrollment. In doing so, we may have masked the disease severity of those who had multiple uses and biased our results toward null. Future researchers should fully use the longitudinal nature of the data for more in-depth analysis.

The data for our projected cost-savings are limited by the lack of enrollment continuity of members into the full-risk insurer leading to fluctuations in the total number of patients claims data each month. However, the theme has been consistent yearly where we have observed continued decrease in total costs of care each year enrolled in the program. Although we acknowledge the possibility of regression to the mean, such a trend is not typically observed clinically in our patients with extreme medical complexity, and the financial argument that has been presented to our hospital leadership has been compelling enough to sustain and grow the program.

Despite the reliance of many CMC on several home-based care services, resources to provide high quality home-based care are extremely limited.<sup>19</sup> Home-based medical care for CMC is rarely discussed, but given the increasing evidence and need for home-based primary care in medically complex adults, a model for CMC seems only natural.<sup>20</sup> In our own experience, partnering with adult programs has been advantageous in piloting innovative approaches in home care, sharing resources, and unified advocacy.

The Pediatric Visiting Doctors and Complex Care Program is a unique model of care

that emphasizes the importance and value of providing care at home for CMC. Our program is one of the few academic center–based home visiting programs for CMC. Replication of this model will require institutional support and sustainability is most feasible in partnership with payers as value-based care reimbursement models emerge. Future directions of our program include providing hospital-at-home care, increasing educational experiences for trainees, addressing the mental health needs of caregivers, and offering multispecialty visits, including having other subspecialties integrated to home visiting or telemedicine. Future research opportunities include identifying which elements of the program have the greatest impact on use and how to maximize cost-savings for the institution.

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