


# The Influence of Care Coordination on Patients With Special Health Care Needs in a Pediatric Residency Continuity Clinic

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## Abstract

This study evaluates the influence of comprehensive health care coordination for children with special health care needs (CSHCN) in a resident continuity clinic. CSHCN patients were identified from 2 resident continuity panels. Patients were eligible with a score of 2 or greater on the CSHCN screener. Interventions included extended appointment times, a binder, and direct phone access to the social worker who facilitated follow-up appointment scheduling. Data measured included completed and no-show visits for primary care and subspecialty appointments, hospitalization and emergency department visits, use of binders, and parent satisfaction surveys. Patients with a baseline CSHCN screener score  $\geq 4$  were 15.6 times more likely to keep their appointment after enrollment ( $P = .0035$ ). Mental health no-show visits decreased significantly ( $P < .0001$ ). The utilization of components of comprehensive team-based care coordination, even with limited resources, can improve the delivery of health care for children with complex medical needs and mental health disorders in a resident-based clinic.

## Keywords

Care coordination, continuity clinic, children with special health care needs

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## Background

The prevalence of children with special health care needs (CSHCN) has increased in the last 15 years from 12.3% to 15.1% in 2010 due to improved survival from once-fatal diseases.<sup>1</sup> The US Department of Health and Human Services Maternal and Child Health Bureau has defined children and youth with special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”<sup>2,9,13</sup>

The care of CSHCN is complex and utilizes systems-based services involving access to a medical home as well as community and financial resources. This makes CSHCN a vulnerable population at extremely high risk for poor outcomes. The American Academy of Pediatrics supports the concept of the “medical home” and describes

it as a care system that seeks and acknowledges a shared responsibility with the family and the community for the complete care of the child. Such care must be accessible, comprehensive, continuous, coordinated, compassionate, and culturally competent.<sup>2</sup> Care coordination within the medical home involves identifying, assessing, planning, implementing, and evaluating options and services specific to that child’s and family’s needs.<sup>2–4</sup> Studies have shown significant benefits of care coordination models, including reduced hospitalizations, decreased emergency department (ED) visits, improved patient satisfaction, and

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enhanced opportunities for clinical process improvements.<sup>2,5</sup> Inherent in dynamic care coordination is the role of the primary care physician (PCP) as advocate and participant. The PCP must face the challenge of disease management in this context to provide consistency of care, communicate effectively, collaborate with community resources, and understand the functional consequences of illness and its impact on children and their families.

As many practicing pediatricians feel they lack the skills to manage children with complex medical problems and because CSHCN are often served by safety-net providers in residency clinics who see a disproportionate number of patients insured through Medicaid, there is a dire need to prepare resident physicians for the growing number of CSHCN under their care in a continuity setting.<sup>6,7,11</sup> A gap exists between evidence-based care for patients with complex, chronic illness and the training of physicians who care for those patients.<sup>8</sup> Furthermore, continuity defined as an uninterrupted succession of services by a single provider or group of providers improves health care quality through the relationship that develops between the provider and the patient.<sup>5</sup> However, both training of resident physicians and continuity are currently difficult to achieve in a resident clinic setting due to work hour restrictions and limited time in the outpatient setting.

Our study sought to incorporate comprehensive care coordination at a pediatric resident continuity clinic based at a Federally Qualified Health Center serving a high-risk and low-income population in Peoria, Illinois. Thirty pediatric and medicine-pediatric residents each spend one-half day per week at the clinic for their continuity experience. Resident barriers to continuous care that we identified included frequent clinic cancellations due to vacation and during high-acuity rotations, which limited the PCP availability. Identified patient barriers included limited access to providers through visits and phone calls, transportation needs, lack of ease of referral to subspecialists, and lack of identification of the resident PCP. We hypothesized that comprehensive care coordination for CSHCN would increase continuity with the PCP and improve patient satisfaction as well as decrease ED/urgent care visits and unscheduled hospitalizations due to better continuity with the PCP. We also compared subspecialty visits, continuity/clinic appointments with the PCP, no-show rates, and patient satisfaction for each enrolled patient for the 1-year period prior to enrollment to the 1-year period after enrollment.

## Methods

Two senior residents supervised in continuity clinic by the same attending on the same half-day at Heartland

Health Services-Armstrong were selected for participation in the study in order to ensure maximal continuity for patients. These group of providers were the same each Tuesday morning, whereas the other half-days in the clinic did not allow for such consistency. Team members for the study included the 2 panel residents, 2 attendings, 1 social worker, and 2 pediatric nurses. The 2 residents had 145 patients who identified the residents as their primary care providers. Each individual resident panel was not assessed for the level of medical complexity prior to the start of the project.

Each patient was reviewed by 2 providers (resident and attending) with the CSHCN screener (CS) and was considered to have special health care needs if he or she had a score of 2 or higher. For each patient, a manual chart review of the electronic medical record was performed for the past year. The CS has been used nationally to identify children with special needs. Rather than relying on a patient's primary diagnosis, it focuses on children who experience significant health consequences due to a variety of health conditions expected to last at least 12 months in duration.<sup>10,14</sup> These conditions are outlined based on 5 criteria: (1) need or use of prescription medications, which included medications for maintenance therapy of a chronic disease process; (2) an above-routine use of services defined as greater than 2 visits to a medical facility (clinic, ED, urgent care, hospitalization) that excluded well-child checks; (3) need or use of specialized therapies or services, which included any referral to a subspecialist, including behavior and developmental caregivers; (4) need or use of mental health counseling, which involved a patient seen by psychiatry, psychology, or a mental health counselor; or (5) a functional limitation defined as either a physical limitation requiring the use of assistive devices for activities of daily living (eg, wheelchairs, walkers, etc) or verbal limitation due to a medical/mental health condition. If the patient had 2 or more of the aforementioned conditions, they were eligible for the study. Although the CS defines a CSHCN with a score of 1, our study used a stricter criterion of a CS score of 2 or higher for patients to ensure that those enrolled in the study were truly in need of care coordination. For example, a score of 1 would be given to a patient who had 2 visits to the ED for the same minor problem in a short time frame, thus falsely labeling the patient as CSHCN.

Fifty-five patients were identified for enrollment with a CS score of  $\geq 2$ . The enrollment period for the patients began after institutional review board (IRB) approval in December 2015 and ended in June 2016. Patients were excluded from the study if they refused enrollment, were no longer able to schedule appointments during resident panel appointment times, no-showed appointments

during the enrollment period, or planned to move out of the area. Of the 55 patients eligible for enrollment, 27 patients enrolled into the study. The study period lasted 12 months for each patient.

Enrolled patients were scheduled for office visits from December 2015 to June 2017. Participants received an initial 1-hour visit and follow-up 40-minute visits. The visits included the following: (1) face-to-face time with the resident PCP, attending, and social worker; (2) direct phone access to our social worker who was identified as their primary contact; (3) follow-up appointments scheduled by the social worker during the course of the visit; and (4) a care coordination binder updated at each visit to include copies of the patient's pertinent medical records, physician names and contact information, and a medication list. In addition to the interventions, the patients' progress and treatment plans were discussed each month with the team members. The patients were scheduled to be seen at least every 3 months, and patients who did not show or were at risk of being lost to follow-up were contacted by the social worker. In addition, a patient satisfaction survey, developed by the Center for Medical Home Improvement of Crotched Mountain (Family/Caregiver Survey, November 2004), was administered to the patient families on enrollment and the same survey was given every 3 months. This Family/Caregiver Survey was a nonvalidated survey that included a combination of 17 questions that encompassed the domains of difficulty in caring for a child with chronic medical problems, caregiver/family stress levels, and office and PCP satisfaction. Four of the 17 questions were taken from the National Survey of Children with Special Healthcare Needs. The questions were multiple choice with answers escalating in degree of severity. There was also a section for comments at the end of the survey.

Data were collected for the period 12 months prior to enrollment and the length of the study through review of the electronic medical record and the local health information exchange. The local health information exchange included any subspecialty, ED/urgent care visits, and hospitalizations that could be accessed by our electronic medical record from outside of our home institution. Patients served as their own historical controls. Data included completed and no-show visits for primary care and subspecialty appointments, hospitalizations and ED visits, specific providers seen in the continuity clinic, the use of care-coordination binders, and parent satisfaction surveys. Subspecialty visits included both physician and nonphysician specialties, such as physical therapy, speech therapy, developmental therapy, and counseling. In addition, care coordination binders were tracked for use if the patient brought the binder to each PCP visit.

After checking the data distributions, we used Wilcoxon signed rank test to compare the difference between preenrollment and postenrollment in terms of the number of continuity scores, subspecialty visits, ED visits, and hospitalizations. Continuity scores are defined as the total number of visits to the clinic divided by the total number of visits by the PCP. In addition, when analyzing the no-show rate, we used generalized estimating equations with logic link to evaluate the difference in the likelihood of no-show since the outcome variables were correlated with each other. We adjusted the baseline CS scores for the multivariate analysis since we found significant differences in the postenrollment data. The variables included in the multivariate analysis are access to transportation, ethnicity, language spoken at home, insurance type, education level of parents, and the number of caregivers at home.<sup>12</sup> Both the multivariate analysis and univariate analysis showed consistent results with each other. The 2-tailed  $P$  values were calculated for all tests, and  $P < .05$  was considered statistically significant. SAS 9.4 (SAS Institute Inc, Cary, NC) was used for all data analysis.

### *Ethical Approval and Informed Consent*

The University of Illinois College of Medicine at Peoria IRB has determined that this project (812342-1) does not meet the definition of human subject research under the purview of the IRB according to federal regulations.

### **Results**

A total of 27 patients were enrolled in our study. Three patients left the Peoria area before the study period ended. Thus, data were analyzed for 24 patients. There were 15 male patients. The majority of patients had public insurance, had a high school education level, and spoke English. Patient demographics are listed in Table 1.

### *Scheduled Outpatient Visits*

We analyzed scheduled outpatient visits. Continuity of care by the resident PCP was compared between pre-enrollment and post-enrollment with the continuity score, which is defined as the total number of visits to the clinic divided by the total number of visits by the PCP. The average continuity score was 60% with a 0.37% standard deviation (SD) for the pre-enrollment and 75% with 0.22% SD for the post-enrollment. The median continuity scores were 64% and 71% for pre-enrollment and post-enrollment, respectively. Although the average continuity score was 15% higher in the post-enrollment, the difference was not statistically significant ( $P = .064$ ). In

**Table 1.** Demographics of Enrolled Children With Special Health Care Needs.

	N	%
<b>Gender</b>		
Male	15	62.5
Female	9	37.5
<b>Race</b>		
African American	13	54.2
White	6	25
Other (Latino/Asian)	5	20.1
<b>No. of caregivers in home</b>		
One	12	50
Two or more	12	50
<b>Parent education level</b>		
Some high school or less	1	4.2
High school/GED	19	79.2
Some college or more	4	16.6
<b>Insurance status</b>		
Private	1	4.2
Public	21	87.5
No insurance	2	8.3
<b>Language spoken at home</b>		
English	21	87.5
Spanish	3	12.5
<b>Primary transportation</b>		
Own car	15	62.5
Other—bus, taxi, friends	9	37.5
<b>Patient enrollment CS score</b>		
<4	18	75
≥4	6	25

Abbreviation: CS, children with special health care needs screener.

addition, the number of total completed visits to the PCP increased from 62 in the pre-enrollment year to 88 in the post-enrollment period, which was a 30% increase but did not show a statistical difference. The total number of subspecialty visits decreased from 85 in the pre-enrollment year to 70 in the post-enrollment period, which was a positive 17.7% change. However, when we examined the change in the number of subspecialty visits for each patient, we did not find a significant difference ( $P = .3253$ ). The mean (SD) and median for subspecialty visits were 3.5 (4) and 3 for pre-enrollment and 2.9 (4.3) and 1 for post-enrollment. When our population of patients was stratified on the basis of CS severity, we found that patients in the study with a baseline CS score  $\geq 4$  were 15.6 times more likely to keep their scheduled appointments for both PCP and subspecialty visits in the post-enrollment period ( $P = .0035$ , odds ratio = 15.6, 95% confidence interval = 2.5-98.4). However, there were only 6 patients with a baseline CS score  $\geq 4$  allowing for the higher confidence intervals.

We analyzed no-show visits with the resident PCP and subspecialists. The no-show rates in our practice revealed no significant differences in the pre-enrollment and post-enrollment periods ( $P > .05$ ) between and within the PCP group versus other providers. We further analyzed no-shows specifically for mental health visits. Mental health visit no-shows decreased significantly in the year post-enrollment at 11% compared with pre-enrollment at 54% ( $P < .0001$ , odds ratio = 8.4, 95% confidence interval = 6.3-11.2) for patients under the care of PCP providers.

Access to transportation, ethnicity, language spoken at home, insurance type, education level of parents, and number of caregivers at home did not have a significant impact on overall no-show rates.

### ED/Urgent Care Visits and Hospitalizations

The ED/urgent care visits decreased in the year after enrollment into the study. ED visits decreased by 32% from 38 visits (average  $\pm$  SD of  $1.58 \pm 2.17$  per patient) in the pre-enrollment period to 26 (average  $\pm$  SD of  $1.08 \pm 1.32$  per patient) in the post-enrollment period ( $P > .05$ ). Unscheduled hospitalizations decreased by 50% from 4 admissions ( $0.17 \pm 0.6$ ) to 2 admissions ( $0.08 \pm 0.28$ ;  $P > .05$ ). These differences were not statistically significant.

### Patient Satisfaction Survey

Twenty-seven patient satisfaction surveys were obtained on the day of enrollment. The latter was referred to as survey #1 and served as a measure of baseline satisfaction prior to the intervention. Surveys were obtained every 3 months after enrollment if the patient showed up for their scheduled visits (surveys #2, #3, and #4). There was no significant difference in patient satisfaction survey results pre-enrollment and post-enrollment.

### Discussion

Studies have shown comprehensive team-based care coordination for children with chronic medical conditions is associated with increased quality of care and decreased resource utilization. However, care coordination is not prevalent in resident continuity clinics.<sup>6,8</sup> To improve delivery of care to CSHCN, our pediatric resident clinic at Heartland Community Health Clinic-Armstrong in Peoria, Illinois, implemented a team-based care coordination model for complex patients in 2 resident continuity panels. The most significant effects found after implementing this care model were the greater likelihood of those patients with the highest (ie,

$\geq 4$ ) CS score keeping their appointments and the reduction in no-show rates for mental health visits independent of CS scores.

Many factors limit patient-physician continuity of care, especially in a resident clinic. Duty hour restrictions and clinic cancellations (post call, on call, mandatory vacations) may limit residents' accessibility to their patients. Despite these restrictions, it is imperative to ensure continuity for CSHCNs so that residents have greater knowledge of their patients and are able to focus on their patients' specific needs during each visit. Continuity of care increases trust for the provider and the medical team and leads to a better patient-physician relationship with improved adherence to physician recommendations and satisfaction with primary care.<sup>5</sup> This study enabled continuity by incorporating the social worker as a liaison who closely monitored the resident PCP schedules to ensure integrity of the PCP relationship and was available for direct contact with patients who needed to reschedule their appointments. The face-to-face encounter between the social worker and patient as well as attending and patient provided another level of continuity during the office visit, which was vital to maintaining continuity when the patient did have to see another provider for a visit. Many clinics have dedicated complex care managers/coordinators, but in clinics that do not have these resources, creating a limited process to utilize existing resources such as a social worker can be a lifeline for these patients.

Another desired outcome of our study was to decrease the patient no-show rates for scheduled appointments; however, the overall patient no-show rates with the resident PCPs compared with the other providers in the clinic failed to show any difference. This may be the result of a spuriously low pre-enrollment no-show rate, as the total number of pre-enrollment appointments made was low (1 or 2 visits) for several patients. In addition, many patient barriers (social, environmental, physical) could not be addressed during the study period. For example, a patient who had transportation issues prior to enrollment and was unable to make it to a scheduled appointment may have continued to have transportation barriers throughout the study. Although social workers attempt to address barriers such as transportation issues, the clinic is still limited by funds that are allocated for those resources. Overall, we believe that more consistent contact with our social worker, increased number of clinic visits with longer appointment times, and better PCP continuity led to stronger physician and clinic relationships.

Although the overall no-show rate remained the same, the study showed that complex patients with a screener score  $\geq 4$  and patients with mental health subspecialty visits were more likely to keep his or her

appointment during the study period. Hence, the complex medical patients and mental health patients demonstrated better utilization of care coordination. Our study highlights that subpopulations of CSHCN may benefit more from comprehensive team-based care coordination and can be targeted in clinics with limited resources or a large number of patients with special health care needs.

In our study, ED/urgent care visits, hospitalizations, and subspecialty visits all decreased but may not have had enough power to show statistical significance. Numerous other studies, including a study at UCLA in a residency continuity clinic, have shown that care coordination services decrease ED visits.<sup>5</sup> Increased visits to our clinic may have led to more comprehensive management by the PCP as well as better familiarity with our nurses, social worker, and health care system and may have decreased ED/urgent care visits, subspecialty visits, and unscheduled hospitalizations. The decrease of subspecialty visits may appear as a negative outcome; however, improved PCP visits can lead to earlier detection of chronic disease and management and further reduce the overuse of resources. As ED visits and hospitalizations maybe the most expensive form of health care delivery, the decrease of both resources would likely result in decreased health care costs.

Studies have also shown improved patient satisfaction with the team-based care coordination model, but we were unable to demonstrate this. Our survey was not validated, and the baseline surveys showed high levels of satisfaction, which made it difficult to assess trends. Furthermore, the emotional state of the patient on any visit may have affected survey results in a way that could not be overcome with the number of data points we had.

The results of this study are encouraging but have several limitations. The number of subjects in the study was small, and only 2 resident panels were assessed. Many patients had barriers to care that we could not alleviate. Binders were often not brought to clinic appointments so their benefits could not be adequately determined. Resident schedules continued to be limited due to duty hour restrictions despite efforts to preserve continuity, and the longer appointment times further limited the schedules. Nevertheless, our study at Heartland Health Services-Armstrong suggests that even with limited resources, the utilization of components of comprehensive team-based care coordination, can improve the delivery of health care for children with complex medical needs and mental health disorders.

Future study requires recruitment of a larger pool of patients and investigation of which subgroups of CSHCN patients may benefit more from care

management programs. Our study together with other published reports argues that care coordination should be integrated across all resident panels in order to standardize care and promote best practices, improve continuity and care team collaboration, and foster resident education and a desire to care for CSHCN in residents' future practices. Engagement with community stakeholders is necessary to adequately address patient barriers to health care access. Finally, a validated survey for CSHCN and their families is needed to better assess quality of life, patient and family satisfaction, and emotional wellness.

### Author Contributions

Dr. Moeenuddin, Dr. Kim-Kumpfer, Dr. Owchar, and Dr. Baker contributed to conception, design, and completion of the analysis and writing of the manuscript. Amy Duffield assisted in data acquisition. Dr. Santoro mentored and edited the final proofs.

### Declaration of Conflicting Interests

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### References

- Stein RE. Chronic physical disorders. *Pediatr Rev.* 1992;13:224-230.
- American Academy of Pediatrics Council on Children with Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics.* 2005;116:1238-1244.
- Kuo D, Turchi R. Best practices: caring for the child and youth with special health care needs. *Contemp Pediatr.* 2010;8:36-49.
- Van Cleave J, Boudreau AA, McCallister J, Cooley WC, Maxwell A, Kuhlthau K. Care coordination over time in medical homes for children with special health care needs. *Pediatrics.* 2015;135:1018-1026.
- Klitzner TS, Rabbitt LA, Chang RR. Benefits of care coordination for children with complex disease: a pilot medical home project in a resident teaching clinic. *J Pediatr.* 2010;156:1006-1010.
- Nazarian B, Glader L, Choueriri R, Shipman DL, Sadof M. Identifying what pediatric residents are taught about children and youth with special health care needs and the medical home. *Pediatrics.* 2010;126(suppl 3):S183-S189.
- Council on Community Pediatrics. Poverty and child health in the United States. *Pediatrics.* 2016;137:1-14.
- Stevens D, Bowen J, Johnson J, et al. A multi-institutional quality improvement initiative to transform education for chronic illness care in resident continuity practices. *J Gen Intern Med.* 2010;25(suppl 4):S574-S580.
- Perrin EC, Newacheck P, Pless B, et al. Issues involved in the definition and classification of chronic health conditions. *Pediatrics.* 1993;91:787-793.
- Bethell CD, Blumberg SJ, Stein RE, Strickland B, Robertson J, Newacheck PW. Taking stock of the CSHCN screener: a review of common questions and current reflections. *Acad Pediatr.* 2015;15:165-176.
- AAP National Center for Medical Home Implementation. Educating residents on medical home. [www.medicalhomeinfo.org/training/residency](http://www.medicalhomeinfo.org/training/residency). Accessed December 2015.
- Newacheck PW, Kim SE, Blumberg SJ, Rising JP. Who is at risk for special health care needs: findings from the National Survey of Children's Health. *Pediatrics.* 2008;122:347-359.
- Brown N, Green J, Desai M, Weitzman CC, Rosenthal MS. Need and unmet need for care coordination among children with mental health conditions. *Pediatrics.* 2014;133:e530-e537.
- The Child and Adolescent Health Measurement Initiative. The children with special health care needs (CSHCN) screener. <http://www.cahmi.org/wp-content/uploads/2014/06/CSHCNS-Survey-and-scoring.pdf>. Accessed April 25, 2019.