

Benefits of Care Coordination for Children with Complex Disease: A Pilot Medical Home Project in a Resident Teaching Clinic

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Objective To study the integration of comprehensive care coordination for children with complex disease in our resident education clinic at University of California Los Angeles by analyzing alterations in medical resource use.

Study design The Pediatric Medical Home Project at University of California Los Angeles was designed to include 4 basic elements: 1) 60-minute intake appointment; 2) follow-up appointments twice the length of a standard visit; 3) access to a “family liaison”; and 4) a family notebook (“All about Me” binder). From the initial cohort of 43 patients, encounter data on 30 were analyzed to determine use of outpatient, urgent, emergency department (ED), and inpatient services. Encounters for each patient were compared for a period of 1 year before and 1 year after enrollment.

Results The average number of ED visits per patient decreased from 1.1 ± 1.7 before enrollment to 0.5 ± 0.9 after medical home enrollment ($P = .02$). However, no significant change was found in use of any of the other health care resources studied.

Conclusions Incorporating a program of care coordination according to the principles of the medical home into an outpatient pediatric residency teaching clinic may not only serve as a training vehicle for pediatric residents, but also create favorable alterations in medical resource use. (*J Pediatr* 2010; ■: ■-■).

The provision of medical care to children with complex chronic conditions can be difficult, particularly for children living in challenging socioeconomic circumstances. The American Academy of Pediatrics has been promoting the concept of the “medical home,” which is defined by the Academy as an approach to complex care coordination and not a location of care provision, to aid in the care of medically complex, socially fragile children.¹ The medical home is designed to provide a constant, trusted source of care, typically a general pediatrician in a pediatric office setting. Although a number of studies have focused on the factors that determine access to a usual source of pediatric care² or have attempted to demonstrate the efficacy of care coordination for children with specific conditions such as asthma,³ there is a growing body of evidence on the efficacy of care coordination designed according to the principles of the medical home when applied to higher risk populations, such as children with chronic conditions⁴⁻⁷ or children living in rural areas.⁸ Antonelli et al published a cost and outcome analysis of care coordination for children with special health care needs (CSHCN) in multiple independent primary care practices, studying a wide range of patient acuity and complexity.⁹

The benefits of care coordination using the medical home model has become an established part of the dialogue on health care reform and specifically in addressing improvements in pediatric health care delivery. However, the feasibility of comprehensive care coordination, as envisioned in the medical home concept, on a large scale remains uncertain. A need has been identified to enhance training opportunities for primary care providers to achieve consistency with an expanded role in managing chronic conditions in children.^{10,11} The effort to train pediatricians in the principles of care coordination may benefit from the fact that training for pediatric residents often involves the delivery of general pediatric care to the very complex patient population cared for at tertiary pediatric teaching hospitals. However, the demands of residents’ schedules do not allow for easy access of patients to their resident physicians, creating barriers to the provision of comprehensive care on a continuous basis.

Accordingly, we sought to develop a pilot program to integrate a comprehensive care coordination model for children with complex disease in the residency training program in the resident education clinic (Pediatric Continuity Clinic) at the Mattel Children’s Hospital at the University of California Los Angeles (UCLA). The Pediatric Medical Home Project at UCLA for Children with Special Health Care Needs became operational in 2003, with funding from the Healthy Tomorrows Partnership for Children. We sought to develop a working medical home care coordination model while building a pediatric resident physician training curriculum on the basis of medical home principles and best practices. We hypothesized that care coordination organized along American Academy of Pediatrics medical home guidelines for CSHCN, while providing a vehicle for resident education, might also alter patterns of medical resource use by shifting care away from the

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| CSHCN | Children with special healthcare needs |
| ED | Emergency department |
| UCLA | University of California Los Angeles |

emergency department (ED). As part of our evaluation of the project, we examined ED, urgent care, and inpatient encounters for each enrolled medical home patient for a 1-year period before enrollment in the Medical Home Project and for a 1-year period after enrollment.

Methods

Patients are eligible for enrollment in the Pediatric Medical Home Project at UCLA when they are residents of Los Angeles County and receive their primary pediatric care in the Pediatric Continuity Clinic at the Mattel Children's Hospital at UCLA. In addition, all patients must have diagnoses for which they see at least 2 different pediatric subspecialists on an ongoing basis. Patients who have received, or who are currently listed for, solid organ transplants and patients seen in adolescent continuity settings were excluded from the study because these programs have their own independent care coordination structures. Patients <1 year old at the time of enrollment were excluded from this study because of the confounding effect that might result from intensified medical resource use in the first year of life. All patients in the Medical Home Project are recipients of Medicaid. This study was approved by the institutional review board at UCLA.

The study population comprised patients enrolled in the Pediatric Medical Home Project at UCLA for Children

with Special Health Care Needs between September 2003 and December 2004 for whom data were available for 1 full year before and 1 full year after enrollment and who met enrollment criteria for this study (Table I). These patients receive most of their medical care at the Mattel Children's Hospital at UCLA, which is a tertiary/quaternary pediatric medical center. Thus, the data available for this study encompass most, if not all, of the care provided to study subjects during the periods being analyzed.

The Pediatric Medical Home Project at UCLA for Children with Special Health Care Needs was initiated in the resident continuity clinic at the Mattel Children's Hospital in the fall of 2003. At that time, each resident was scheduled to see 3 patients per hour (20 minutes per visit). As part of the Medical Home Project, patients were seen by resident pediatricians during visits staffed by the regular teaching pediatric faculty. Medical home patients seen in the resident continuity clinic were encouraged to identify themselves as belonging to the Medical Home Project. Medical home visits differed from typical resident continuity visits in 4 ways: (1) Each patient was scheduled for an initial 60-minute visit for a comprehensive clinical and social evaluation; (2) Follow-up appointments for medical home patients were 40 minutes, which is twice the length of a standard visit; (3) Patients were assigned a "family liaison," who served as a primary contact for the family, attended most appointments, provided translation services, and coordinated follow-up appointments and

Table I. Study patient characteristics

| Sex | Age (years) when enrolled | Pediatric subspecialty services |
|-----|------------------------------|---|
| F | 5.0 | Genetics, orthopedics, plastic surgery, ophthalmology |
| M | 3.6 | Urology, gastroenterology, head and neck surgery, neurosurgery |
| F | 1.6 | Gastroenterology, cardiology, endocrinology, developmental pediatrics, ophthalmology |
| F | 2.3 | Gastroenterology, head and neck surgery, neurology, cardiology |
| M | 10.7 | Neurology, pulmonology, gastroenterology, psychiatry, cardiology |
| F | 3.8 | Neurology, gastroenterology, head and neck surgery |
| F | 5.9 | Ophthalmology, pulmonology, cardiology, head and neck surgery |
| F | 9.0 | Endocrinology, head and neck surgery, neurology, ophthalmology |
| F | 4.1 | Gastroenterology, genetics, orthopedics, plastic surgery, cardiology |
| F | 12.3 | Gastroenterology, ophthalmology, cardiology, endocrinology, allergy/immunology |
| F | 2.6 | Gastroenterology, genetics, orthopedics, plastic surgery, pediatric surgery, head and neck surgery |
| F | 9.0 | Urology, endocrinology |
| M | 8.4 | Neurology, gastroenterology |
| F | 4.3 | Nephrology, neurology, developmental pediatrics, cardiology |
| F | 13.2 | Cardiology, psychiatry |
| F | 11.4 | Gastroenterology, endocrinology, neurology, genetics, orthopedics, plastic surgery, head and neck surgery |
| M | 9.4 | Cardiology, orthopedics, psychiatry |
| M | 1.7 | Neurology, ophthalmology, head and neck surgery |
| M | 3.1 | Gastroenterology, ophthalmology |
| M | 9.0 | Ophthalmology, psychiatry |
| F | 1.6 | Cardiology, orthopedics |
| F | 2.7 | Cardiology, allergy/immunology, genetics |
| F | 10.5 | Neurology, cardiology, nephrology, gastroenterology |
| M | 10.0 | Gastroenterology, cardiology, head and neck surgery, neurology |
| F | 12.3 | Cardiology, neurology, head and neck surgery |
| M | 11.4 | Endocrinology, orthopedics |
| M | 6.5 | Pulmonology, neurology, genetics |
| M | 7.9 | Neurology, head and neck surgery, cardiology, gastroenterology |
| M | 13.6 | Urology, pulmonology |
| M | 3.8 | Gastroenterology, neurology |

M, Male; F, female.

procedures (family liaisons are native Spanish speakers recruited for their clinical coordination expertise); (4) Each patient received a family notebook, called the "All About Me" binder, which included, on a constantly updated basis, copies of all of the patient's pertinent medical records, physician names and contact information, and a list of the patient's medications. A distinctive Medical Home Project identifier appears on the binder, the family liaison business cards, and the official inpatient and outpatient medical record. In addition, a special curriculum related to the concepts of the Medical Home Project was developed with the resources of the Healthy Tomorrows Partnership for Children grant (Table II).

We used the electronic medical record for inpatient and outpatient encounters at the Mattel Children's Hospital at UCLA to track medical home patients' use of outpatient, urgent care, ED, and inpatient services. Each patient's number of encounters was determined for a period of 1 year before and 1 year after the date of enrollment in the project in each of these areas: the outpatient clinic, including both primary care and subspecialty visits; the urgent care clinic (same-day appointments for sick children); the ED; and inpatient stays at Mattel Children's Hospital at UCLA. Additionally, we tracked length of hospital stay for each inpatient encounter. This methodology is similar to that used by Berman et al to study the effects of a hospital-based comprehensive primary care clinic on a comparable population of CSHCN.¹² Descriptive statistics were performed on all variables. Continuous variables were characterized by range and mean plus or minus SD. The Kolmogorov-Smirnov test was used to determine whether continuous variables followed a normal distribution. For variables that were normally distributed, comparisons before and after medical home enrollment were made with the paired Student *t* test. For variables that were not normally distributed (number of ED visits and number of inpatient encounters), comparisons before and after medical home enrollment were made with the Wilcoxon rank-sign test. Unless otherwise indicated, data are presented as means \pm SD. A 2-tailed *P* value $<.05$ was considered to be statistically significant. Statistical analyses were performed with SPSS software version 14.0 for Windows (SPSS, Chicago, Illinois).

Results

Between September 2003 and December 2004, 43 patients were enrolled in the Medical Home Project at UCLA. Two patients left the program before participating for 1 full year. An additional 10 patients were enrolled before their first birthday, and 1 patient did not meet study criteria. Thus, data were analyzed for 30 patients. There were 17 female patients, and patients ranged in age from 1.6 to 13.6 years of age (7.0 ± 3.8 years). The patients received ongoing care from an average of 3.5 ± 1.3 pediatric subspecialists (range, 2-6). Spanish was the primary language of the families of most of patients. The second largest group spoke English. Other languages rep-

Table II. Curriculum developed as part of the Healthy Tomorrow's Partnership grant to teach medical home principles to pediatric residents

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| Module 1: Introduction to Medical Home Care |
| Module 2: The System of Care and Children with Special Health Care Needs |
| Module 3: Serving as a Medical Home Provider |
| Module 4: Strategies for Medical Home Care |
| Module 5: Working with Families |
| Module 6: Getting Organized and Getting Services (Parents/Caregivers) |
| Module 7: Coordinating Services in the Medical Homes |

resented in the program were Zapotec, an indigenous language of Mexico, Tagalog, and Portuguese.

ED Visits

In the year before medical home enrollment, 13 patients visited the ED for a total of 34 visits. In the year after enrollment in the Medical Home Project, 10 patients visited the ED for a total of 15 visits. Thus, the average number of ED visits per patient decreased from 1.1 ± 1.7 before enrollment to 0.5 ± 0.9 after medical home enrollment ($P = .02$). Because the number of ED visits was not normally distributed, this data was also analyzed by using the Wilcoxon signed-rank test. This analysis also showed that the number of ED visits decreased significantly in the year after enrollment in the Medical Home Project ($P = .02$).

Scheduled Outpatient Visits, Urgent Care Visits, Hospital Admissions, Total Hospital Days, and Average Length of Stay

We analyzed patient data for scheduled outpatient visits, patient visits to the urgent care walk-in clinic, hospital admissions, total hospital days, and length of stay. The average number of scheduled outpatient visits (20.6 ± 15.7 before medical home enrollment versus 24.9 ± 15.8 after medical home enrollment; $P = .1$), urgent care visits (2.6 ± 3.3 versus 3.3 ± 4.8 ; $P = .45$), hospital admissions (0.9 ± 1.7 versus 1.1 ± 1.2 ; $P = .54$), average hospital days (13.6 ± 41 versus 6.5 ± 9.8 ; $P = .32$), and average length of stay (4.5 ± 13.5 versus 3.1 ± 4.5 ; $P = .54$) showed no significant change in the year after enrollment in the Medical Home Project.

Discussion

Numerous studies have demonstrated the efficacy of care coordination consistent with medical home principles in improving medical outcomes, reducing medical resource use and improving parent satisfaction, especially for children with complex medical conditions.^{4-6,8,9,13,14} In addition, training pediatric residents in the principles of care coordination as embodied in the medical home concept has been advocated by several authors.^{11,15,16} These considerations indicate the need for pilot projects using a medical home model of care coordination in a resident teaching clinic at an academic medical center. We sought to fulfill this need

in developing the Pediatric Medical Home Project at UCLA for Children with Special Health Care Needs.

The results of this study suggest that this approach is feasible and that some of the known benefits of the medical home model may accrue to patients cared for in a residency training clinic. The most positive effect was an apparent reduction in ED use, suggesting that the project promoted the delivery of care in a manner consistent with at least some of the goals of the medical home paradigm.

The decrease in ED visits found in this study is an intended outcome of the medical home model. Consequently, this result is not unexpected, because the importance of continuous, accessible outpatient care has been stressed as part of the medical home concept,^{17,18} and coordination of services between the medical home and the ED has been the subject of earlier publications.¹⁹ Other studies have found decreased ED use as the result of enhanced care coordination services and a family-centered orientation in a variety of pediatric and adult patient populations.²⁰⁻²⁴ One of the aspects of our project that may have enhanced this effect is the use of Spanish-speaking family liaisons. These administrative-level employees focused on helping our clients navigate the complexities of the health care system, which has proven to be difficult for many underprivileged and complex populations.^{25,26} In specific, the family liaison served as the primary contact person for the family, providing a conduit of information for our patients, care coordination, help with insurance issues, basic triage services, and translation for our large number of Spanish-speaking parents. In this capacity, our family liaison was acting as a "health navigator,"²⁷ which is another term that has been coined to describe this function.

Thus, it is possible that parents of our underprivileged, complex patients were empowered by the pediatric residents, supervising pediatric faculty, and the medical home family liaison to use telephone consultation, scheduled outpatient appointments, and urgent care visits to avoid the use of the ED. Although not formally studied, several parents in the project's parent advisory group offered this explanation when the group was shown the data and asked to comment.

During the study period, the entire cost of the Medical Home Project at UCLA was covered by a Healthy Tomorrows Partnership for Children grant totaling \$45000/year in direct costs. This paid for the salary of the family liaison and all program and educational materials. It seems likely that program costs might be substantially offset by reducing use of high-cost medical services such as the ED. The cost savings represented by lower ED use for medical home patients may be considerable because ED visits in particular are the most expensive form of care delivery in the United States.²⁸⁻³⁰ These factors may help offset the increased costs of instituting programs to teach residents medical home principles.

The results of this study, while encouraging, have a number of limitations. Most obvious, the number of patients in the study group is small, raising concerns about type II errors and generalizability of the results. The patients in this study are among the most complex patients cared for at pediatric

tertiary care centers. Consequently, their baseline healthcare resource use would be expected to be high. For this reason, any comparative reduction in resource use could appear more dramatic than would be achieved for less complex populations.

The study uses a pre-post design, which allows for the possibility of contamination of the results by secular trends. For example, ED use may have been decreasing for all pediatric patients at UCLA during the study period. It is also possible that our patients' decline in resource use is the result of advancing age or a positive effect of their medical treatment, resulting in enhanced health of the population with time. We attempted to partially address this effect by excluding all patients <1 year of age. In addition, it is possible that use of ED services outside the UCLA health care system may have occurred and would not have been captured in this dataset. Finally, there may have been a naturally occurring increase in the ability of parents of the children in the study population to navigate the health care system during the period of the study, a phenomenon that has been demonstrated by other authors.³¹

This study did not evaluate the educational goals of teaching pediatric residents the principles of care coordination according to the medical home model. The only evidence of success in this area is occasional anecdotal feedback from the residents. A formal evaluation of the educational values of the Medical Home Program is needed and will be undertaken in the future.

Our results suggest that incorporating an organized program of care coordination such as the Medical Home Project at UCLA in an outpatient pediatric residency teaching clinic may not only serve as a vehicle for training pediatric residents in the principles of the medical home, but also have the potential to decrease use of ED services. ■

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