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# Association of Care in a Medical Home and health care utilization among children with Sickle Cell Disease

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## Abstract

**Objective—**Sickle cell disease (SCD) is marked by high utilization of medical services. The aim of this study was to determine whether having a patient-centered medical home (PCMH) is associated with a reduction in emergency care (ED) utilization or hospitalizations among children with scd.

**Methods—**We collected and analyzed data from parents of 150 children, ages 1 to 17 years, who received care within a large children's hospital. The primary dependent variables were rates of parent-reported ED visits and hospitalizations. The principal independent variable was parent-reported experience with an overall PCMH or its four individual components (regular provider, comprehensive care, family-centered care, and coordinated care). Multivariate negative binomial regression, yielding incident rate ratios (irr), was used for analysis.

**Results—**Children who received comprehensive care had half the rate of ED visits (IRR 0.51, 95% confidence interval, 0.33-0.78) and nearly half the rate of hospitalizations (IRR 0.56, 95% confidence interval, 0.33-0.93) compared to children without comprehensive care. No other component of the PCMH was significantly associated with ED visits or hospitalizations. Children reported to have excellent/very good/good health status had lower odds of ED visits and hospitalizations compared to those reported to be in fair/poor condition.

**Conclusions—**Children with SCD reported to experience comprehensive care had lower rates of ED encounters and hospitalizations after controlling for demographics and health status. The overall findings highlight that the provision of comprehensive care - having a usual source of care and no problems with referrals - may provide a strategy for improving pediatric SCD care.

### Keywords

Sickle cell disease; Epidemiology; Outcomes research

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## INTRODUCTION

The care of children with sickle cell disease (SCD) is marked by substantial utilization of health care services. Despite advances in the clinical management of SCD,[1-6] multiple studies demonstrate that children with SCD continue to rely heavily on acute care services, including emergency (ED) departments and inpatient hospitalization.[7-18] Additionally, higher levels of acute care visits have been documented among children with SCD compared to the general population and children with other chronic conditions.[12, 19-22] These utilization patterns contribute significantly to the economic burden of SCD.[23]

Within the population of children with SCD, use of high-acuity services, including the ED and inpatient wards, may represent inadequate primary care. Receipt of care in high-acuity environments can be problematic for children with SCD. They may be cared for by staff unfamiliar with their extensive histories and medical needs. Such fragmented care may lead to unnecessary testing, resource-intensive interventions, and medical errors. Furthermore, preventable encounters in high-acuity settings may increase exposures to pathogens from other sick children and precipitate serious illness.[24]

High-quality primary care has the potential to limit such preventable and costly interactions with the health care system. The patient-centered medical home (PCMH) is emerging as a cornerstone of efforts to reform the U.S. health care system and establish primary care as a centerpiece for improving health care quality.[25-27] National initiatives increasingly propose that all children, especially those with chronic conditions, have a PCMH.[28] The American Academy of Pediatrics (AAP) currently defines a PCMH as care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.[29] Studies on PCMH have demonstrated multiple benefits, including improved health outcomes, timeliness of care, lower health care costs, increased patient satisfaction, and improved family functioning.[30,31] Although numerous studies have documented health care utilization and medical expenditures associated with pediatric SCD, relatively few have assessed the association between high-quality primary care and patterns of health care use. Previous studies on the ambulatory experiences of children with SCD have predominantly focused on the relationship between proximity to sickle cell centers and health care utilization with little attention to primary care.[22, 32-35]

The PCMH model of primary care may have particular relevance to pediatric SCD.[36] Children with SCD have multi-dimensional needs whether they be clinical, educational, or social. While comprehensive centers offer unique models of care, they are not accessible to most children with SCD and therefore ambulatory care for these children is primarily provided by primary care physicians.[18, 37] Practices with enhanced care delivery may fill a critical gap, particularly in resource-poor settings. A PCMH model of care may also provide better orientation around the whole child rather than the principal condition of SCD. Children with SCD need coordination between multiple specialists as well as active communication with schools. A PCMH, typically located in the child's community, may better facilitate such interactions. Lastly, a PCMH may provide a source of care for families who would otherwise use the ED for illnesses that could be managed in the outpatient setting. Despite these theoretical benefits specific to SCD, little is known regarding the relationship between having a PCMH and health care use among children with SCD.

The objective of this study was to determine the association between parent-reported experience with a PCMH or its individual components and health care use. We hypothesized that perception of a PCMH, in the domains of a personal provider, comprehensive care, family-centered care, and coordinated care, would be associated with lower rates of ED visits and hospitalizations.

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# METHODS

## Study Design and Source of Data

Data for this cross-sectional study were drawn from a survey conducted among parents of children with SCD at a large children's hospital. A questionnaire was utilized to collect child and family demographic information, parent-reported perceptions of access to primary care, and parent-reported health care utilization. The study was approved by the Institutional Review Board of Baylor College of Medicine, Houston, Texas. Written informed consent and child assent waivers were obtained for all participants.

## Study Population

Participants were recruited during outpatient clinic visits at a sickle cell center or during hospitalizations within Texas Children's Hospital (TCH), a large, urban academic pediatric institution. Subjects were parents or guardians (hereafter parents) of children ages 1 through 17 years with a diagnosis of SCD who had documented visits at the TCH sickle cell comprehensive center for a minimum of 12 months. Eligible parents had children with a diagnosis of either hemoglobin SS Disease or sickle beta zero thalassemia. Exclusion criteria consisted of (1) children with milder forms of SCD (i.e., sickle hemoglobin C disease, sickle beta + thalassemia) or (2) parent inability to comprehend English. Research staff were present in the sickle cell center or rounded with the outpatient hematology service daily from October 15, 2010 to May 4, 2011. Prior to recruitment, all subjects were screened for eligibility. We attempted to recruit all subjects eligible for the study. Prospective parents were initially informed of the study by their child's provider (outpatient) or rounding team (inpatient) prior to recruitment by the research team. Parents were asked to complete a survey instrument assessing access to a PCMH.

## Outcome Measures for Health Care Utilization

The primary outcome measures were rates of parent-reported ED visits and hospitalizations. Questions regarding utilization were adapted from the 2007 National Survey of Children's Health (NSCH), a publicly available survey measuring the health and health care of U.S. children.[38] Emergency care use was assessed by the question: “During the past 12 months, how many times did [CHILD'S NAME] visit a hospital emergency department because of his/her sickle cell disease? This included emergency visits that resulted in a hospital admission.” Hospitalization was examined by the question: “During the past 12 months, how many times was [CHILD'S NAME] admitted to the hospital for the care of his/her sickle cell disease?” For both questions regarding utilization, participants were asked to quantify encounters occurring within TCH versus outside institutions. Parent-reported visits to TCH were verified through comparison to the electronic medical record (EMR). Kendall's coefficients assessed the correlation between parent-reported utilization at TCH and EMR documentation of utilization. These correlated moderately: for frequency of ED visits, $r = 0.5$, $p<0.0001$; for hospitalizations, $r = 0.6$, $p<0.0001$. Given the overall accuracy documented by correlations, we used parent report of overall visits for data analysis.

## Primary Independent Variables: PCMH and Components

The primary independent variable was a composite PCMH determination reflective of the AAP criteria for a PCMH. The composite was constructed from 21 questions within the 2007 NSCH questionnaire intended to assess the AAP construct of a PCMH.[39] The definition of PCMH and its components as enumerated here was derived from a definition set forth and operationalized for the National Center for Health Statistics by an advisory group consisting of the Child and Adolescent Health Measurement Initiative, Maternal and Child Health Bureau, and the NSCH Technical Expert Panel.[40] Endorsed by the National

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Quality Forum as a valid measure of the medical home, the NSCH definition of the PCMH and its components has been extensively used in pediatric studies.[31, 41-45] The scoring algorithm developed by the advisory group uses a dichotomous PCMH composite measure that classifies children as having or not having a PCMH. The components of the PCMH operationalized in the NSCH are shown in Table 1. Of the AAP PCMH attributes, continuous and accessible care are not assessed given the limitations of a point-in-time survey in measuring these components via parent report.

For this study, we scored the PCMH and individual components as validated by the NSCH without adaptations. In order for a child to have a PCMH, the parent must indicate the presence of four components: 1) a provider they consider their child's personal doctor or nurse; 2) comprehensive care; 3) family-centered care (includes questions on compassionate and culturally effective care); and 4) coordinated care (Table 1). If any component is absent, the child is considered not to have a PCMH. In assessing whether a child had a provider, the patient was instructed that “A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as [CHILD'S NAME]'s personal doctor or nurse?” Comprehensive care requires that preventive, primary, and tertiary care needs are addressed by a physician who is able to manage and facilitate all aspects of care. For achieving comprehensive care, a child had to have a usual source of care not based in an emergency care center and have “Not a Problem” obtaining referrals on a scale of “Not a Problem”, “Small Problem”, or “Big Problem.” Family-centered care implies that mutual trust and responsibility exist between the patient's family and the provider. For achieving family-centered care, a child had to have all questions answered “Usually” or “Always” on a scale of “Never”, “Sometimes”, “Usually”, or “Always.” Coordinated care requires that the provider shares information and communicates effectively with the child, family, and consultants while also making necessary linkages to community resources. For meeting criteria of coordinated care, a child had to have all questions answered “Usually” or “Always” on a scale of “Never”, “Sometimes”, “Usually”, or “Always.”

Caregivers were not asked to specify which provider served as the reference for their survey responses (primary care physician versus hematologist). The construct of medical home as defined by NSCH is intentionally designed to determine access to services across a network of care rather than those provided by a specific provider or place given the varying and complex needs of children with chronic conditions.

### Child/Family Characteristics

Child covariates consisted of age, gender, insurance status, and health status. Insurance status was categorized as public versus private insurance. Given that worse health status is strongly associated with increased health care utilization among children with SCD, it was important to control for it in the present study. For describing perceived health status, parents were given the following options: poor, fair, good, very good, or excellent. For the regression analyses, we *a priori* categorized health status as fair/poor versus excellent/very good/good. Given that family-related factors can affect the parent's ability to seek care and their perceptions of the care received, we also included parent variables - relationship to child, gender, marital status, and education. Responses for parent relationship to child were dichotomized as parent versus all other categories. Parent marital status was dichotomized as married versus other. Parent education was categorized as high school or less versus more than high school versus college degree.

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### Statistical Analysis

Statistical analyses were performed using SAS® 9.2 (SAS Institute Inc, Cary, NC). Summary statistics including proportions, means, and standard deviation (SD), were calculated. The PCMH composite measure was calculated from the individual PCMH components included in the survey instrument, as described above. Multivariate negative binomial regression analyses, which can correct for over-dispersed count data, were used to assess associations between the PCMH and health care utilization - ED use, hospitalization. Results are reported as incidence rate ratios (IRRs) for the number of encounters per child. Through three sets of multivariate regression analyses, the primary independent variable of a PCMH was systematically evaluated to determine its relationship with health care utilization: 1) the overall PCMH variable used as a dichotomous (present/not present) independent variable; 2) the PCMH independent variable defined as the number of PCMH components achieved (0, 1, 2, 3, or 4); and 3) the PCMH individual components separately used as independent variables. For all analyses, IRRs and 95% confidence intervals (95% CI) were calculated.

## RESULTS

### Demographic Characteristics

There were 150 children recruited. The participation rate among eligible families approached for the study was 77% (150/196). Reasons for refusal included lack of time to complete the survey instrument and desire to consult with other family members. Demographics of the 46 families who refused participation showed no statistically significant differences with participating families. The demographic characteristics of the children are shown in Table 2. The mean age was 9.1 years of age. Approximately two-thirds of children were publicly insured. Approximately 20% of children were reported to be in fair/poor condition. In terms of parent characteristics, 93% of parents reported to be the child's parent and over 90% of parents were female. A quarter of parents had only a high school diploma or less.

### PCMH and Components

Analysis of the PCMH and its components showed that 91% of parents reported that their child had a personal provider, 67% reported that their child received comprehensive care, 59% reported that their child had family-centered care, and 20% reported that they received effective care coordination. Of the entire sample, only 11% (16/150) qualified as having a PCMH, achieving the required thresholds in all four components.

### Health Care Utilization

Parents reported their children to utilize care both within and outside of TCH. Approximately 20% of ED encounters were reported to occur at institutions outside of TCH. Of all hospitalizations, approximately 8% were reported to occur outside of TCH.

**ED use—**Analysis of ED use showed that 99 children (66 %) had a total of 291 ED encounters. The mean number of ED visits per child was 2.1 (Median = 2, Interquartile Range 1-4). A total of 51 children (34%) had no ED visits. In multivariate analysis of ED use (Table 3), having comprehensive care was associated with a lower rate of encounters compared with not having comprehensive care (IRR 0.51, 95% CI 0.33-0.78). No associations were found between the overall PCMH variable, the remainder of the PCMH components, and ED use. Among socio-demographic variables, children reported to be in excellent/very good/good health had a lower rate of ED encounters (IRR 0.43, 95% CI 0.27-0.68) compared to children in fair/poor condition.

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**Hospitalizations—**In the sample, 78 children (52%) were hospitalized for a total of 174 admissions. The mean number of hospital admissions per child was 1.2 (Median = 2, Interquartile Range 1-3). A total of 72 children (48%) had no hospitalizations. Of the PCMH composite and components, only comprehensive care was associated with the rate of hospitalization. Multivariate analysis (Table 3) showed that having comprehensive care was associated with a lower rate of hospitalizations (IRR 0.56, 95% CI 0.33-0.93). Although family-centered care was not associated with hospitalizations, one question making up this composite was associated with hospitalizations. Children of parents who reported "Usually" or "Always" receiving the specific information needed from providers had a lower rate of hospitalizations (IRR= 0.38; 95%CI=0.14-0.99) compared to those who reported "sometimes" or "never." Among socio-demographic variables, only perceived health status was associated with hospitalizations. Children reported to be in excellent/very good/good health had a lower rate of hospitalizations (IRR 0.52, 95% CI 0.30-0.90) compared to children in fair/poor condition.

### Subgroup Analysis

Given that subjects were recruited from both the sickle cell center and inpatient service, we conducted subgroup analyses to examine potential bias from those who were hospitalized. Of the total population, 137 children were recruited from the sickle cell center and 13 children were recruited from the inpatient service. The two subgroups differed according to health status with 50% of hospitalized children reported to be in fair/poor condition and 20% of children from the sickle center reported to be in similar condition. They also differed according to reporting comprehensive care with 66% of children from the sickle cell center having comprehensive care and 85% of hospitalized children reporting comprehensive care. None of these differences were statistically significant. We conducted multivariate regression with only the 137 subjects recruited from the sickle cell center to determine if the relationships found between comprehensive care and health care utilization persisted after removal of inpatient subjects. As in the primary analyses, children with comprehensive care had a lower rate (IRR 0.46, 95% CI 0.28-0.74) of ED encounters and hospitalizations (IRR 0.45, 95% CI 0.26-0.79) compared to those without comprehensive care.

## DISCUSSION

In this study, parent-reported comprehensive care was associated with half the rate of both ED visits and hospitalizations among children with SCD even after controlling for factors such as health status. To our knowledge, this is the first study to demonstrate a relationship between components of a PCMH and health care utilization within the SCD population. Overall, these results provide new understanding on the relationships between the quality of primary care and high-acuity health care use among a resource-intensive subgroup of children.

Comprehensive care, as defined in this study, consisted of a parent-reported usual source of care not based in the ED and no problems getting referrals to subspecialty care. If children have a usual source of care not based in an ED, they may preferentially seek out services in the outpatient setting where routine care can be optimized, preventing exacerbations of chronic disease. If children cannot receive care from expert clinicians such as hematologists, they may be more vulnerable to exacerbations of their chronic disease, leading to ED encounters and hospitalizations. As exploration of health seeking behaviors was not a goal of this study, future studies should assess how perceived access to outpatient services impact parental decisions about utilization of high acuity services.

Multiple national studies support our findings with respect to comprehensive care. A study by Ryan and colleagues showed that children having different sources of care were 1.8 times

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more likely to have received care in an emergency care setting compared to those with a consistent source of care.[46] Brousseau and colleagues demonstrated that a high level of realized access (defined as getting necessary care and having no problems with referrals to subspecialists) was associated with decreased non-urgent ED visits for children.[47, 48] A more recent study showed that a high level of realized access was associated with a lower rate of hospitalizations among children with special health care needs.[49] Cumulatively, these studies provide compelling evidence that specific aspects of comprehensive care are strongly linked with the use of high-acuity services.

Previous studies on comprehensive care specifically for SCD have predominantly focused on access to sickle cell centers. Such centers may provide in some combination co-located components of care including early diagnosis, education, genetic counseling, nutritional advice, pain management, physical therapy, social services, and access to subspecialists.[5, 22, 32, 33] However, access to sickle cell centers is variable and data regarding the impact of such care on health-related outcomes have been mixed.[22, 32-34] A study by Yang et al. reported that patients cared for in a sickle cell clinic had fewer ED encounters and hospitalizations and lower health care expenditures than those not receiving such services.[22] A study by Shankar et al. showed no clear pattern of improved utilization of medical services in relation to proximity to a sickle cell center.[32]

A number of our negative findings merit discussion. First of all, no relationships were found between health care utilization and perception of access to an overall PCMH, whether measured as a composite measure or a cumulative measure of components achieved. Such broad measures may be limited by the underlying assumption that all components making up the composite or cumulative construct are equal in value. Therefore it is important to examine specific components in combination with larger measures. The study also found no relationship between having a personal provider, family-centered care, care coordination, and health care utilization. Only one question regarding receipt of specific information from providers within the family-centered component was associated with hospitalization. It may be that some components of a PCMH only influence attendance at routine care and healthcare utilization for non-urgent conditions. An alternative explanation is that our sample size was not sufficiently large enough to fully assess these relationships.

Several limitations of the study should be noted. First, the survey instrument measures parent perception of PCMH components rather than actual availability of these components. Parents most likely make decisions based on what they perceive is accessible or available. Therefore parent perception of a PCMH is an appropriate measure for understanding health care utilization. Second, information used to determine a PCMH, health status, and health care utilization came from parent report rather than clinical sources. Parental recall is potentially subject to recall bias. However, as our results demonstrate, children with SCD may seek care at multiple institutions. In future studies, administrative record review through payer databases should be explored as a strategy to capture all medical service use.

A third limitation was that this study was conducted at a single institution with hospitalized children and those receiving specialty clinic services in a large tertiary center. These children may be fundamentally different from other populations in terms of access to care and health care utilization patterns. Parents more motivated about SCD management may be more engaged in preventive care and identifying health care resources, thus lowering health care utilization. Therefore, there is a limit to which our results can be generalized. Finally, as this was a cross-sectional study, causality could not be established. From our study design, it is not possible to tell whether lacking core components of a PCMH led to increased utilization or whether increased utilization led to a perception of inadequate access of PCMH components.

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In conclusion, to our knowledge, this study is the first to examine the relationships between access to the components of a PCMH and use of medical services among children with SCD. Even within a sickle cell center, families report differential access to comprehensive care; however a parent report of comprehensive care is associated with reduced ED utilization and inpatient hospitalizations. The potential implications from this study are that children with SCD benefit from interventions focused on providing them with a usual source of care and enhanced access to subspecialty services. Given the multi-dimensional needs of children with SCD (clinical, educational, social, access), the PCMH model may represent a delivery care mechanism aligned to address the medical vulnerabilities of this population. Future studies should be prospective in nature, comprised of larger sample sizes, and begin to assess causal associations between PCMH components, health care utilization, and health care expenditures.

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## Table 1

The Medical Home Composite, Adapted from 2007 National Survey of Children's Health

| Component | Criteria to be Considered a Medical Home |
|---|---|
| Personal Provider | Yes |
| Comprehensive Care | Usual source of care and not an emergency department |
| | Getting a referral not a problem (if needed) |
| Family centered care | Provider usually/always: |
| | ■ spent enough time |
| | ■ listened carefully |
| | ■ was sensitive to family values and customs |
| | ■ provided needed information |
| | ■ partnered in care |
| | Usually/always able to get someone other than a family member to help interpret (if needed) |
| Care coordination (if needed) | Usually/always get help coordinating care |
| | Usually/always satisfied with communication among providers |
| | Usually/always satisfied with communication between providers, school, and other programs |

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## Table 2

Study Population Demographics and Family Characteristics[a]

| Variable | No. (%) N=150 |
|---|---|
| **Child Characteristics** | |
| Age | |
| 1-5 | 39 (26.0) |
| >5-9 | 46 (30.6) |
| >9-13 | 37 (24.7) |
| >13-17 | 28 (18.7) |
| Gender | |
| Male | 79 (52.7) |
| Female | 71 (47.3) |
| Insurance | |
| Public | 94 (66.7) |
| Private | 47 (33.3) |
| Health Status | |
| Fair/Poor | 32 (22.2) |
| Excellent/Very Good/Good | 112 (77.8) |
| **Caregiver Characteristics** | |
| Relationship to Child | |
| Parent | 136 (93.2) |
| Other | 10 (6.9) |
| Gender | |
| Female | 133 (91.7) |
| Male | 12 (8.3) |
| Marital Status | |
| Married | 60 (41.1) |
| Other | 86 (58.9) |
| Education | |
| High school or less | 35 (24) |
| More than high school | 58 (39.7) |
| College degree | 53 (36.3) |
| **Reported Health Care Use** | |
| Emergency care visits | |
| None | 51 (34) |
| 1 or more | 99 (66) |
| Hospitalizations | |
| None | 72 (48) |
| 1 or more | 78 (52) |

[a]Individual categories may not add to 150 due to missing responses.

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## Table 3

Association between Medical Home Components and Health Care Utilization

| Medical Home Component | IRR (95% CI) |
|---|---|
| ED Utilization | |
| Personal Provider | 0.66 (0.29-1.49) |
| Comprehensive Care | **0.51 (0.33-0.78)*** |
| Family-centered Care | 1.28 (0.83-1.99) |
| Coordinated Care | 0.69 (0.40-1.19) |
| Hospitalizations | |
| Personal Provider | 0.80 (0.29-2.23) |
| Comprehensive Care | **0.56 (0.33-0.93)**** |
| Family-Centered Care | 1.67 (0.98-2.87) |
| Coordinated Care | 0.66 (0.35-1.27) |

* p=0.002

** p= 0.03