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The Medical Home Experience Among Children with Sickle Cell Disease

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Abstract

Background—While a large body of research documents acute care services for children with sickle cell disease (SCD), little is known about the primary care experiences of this population. The goal of this study was to determine to what extent children with SCD experienced care consistent with a patient-centered medical home (PCMH).

Procedure—We collected and analyzed data from 150 children, ages 1 to 17 years, who received care within a large children's hospital. The primary dependent variable was access to a PCMH or its four individual components (regular provider, comprehensive care, family-centered care, and coordinated care) as determined by parental report. Multivariate logistic regression was conducted to investigate associations between socio-demographic variables and having access to a PCMH.

Results—Only 11% (16/150) of children qualified as having a PCMH, achieving the required thresholds in all four components. Approximately half of children had access to 2 or fewer components. Over 90% of children were reported to have a personal provider. Two-thirds of children had access to comprehensive care. Almost 60% of children were reported to receive family-centered care. Only 20% of children had access to coordinated care. No consistent associations were found between socio-demographic variables and having access to a PCMH or its individual components.

Conclusions—Within our study sample, children with SCD experienced multiple deficiencies in having access to a PCMH, particularly with respect to care coordination. However, further studies with larger samples are needed to determine associations between socio-demographic variables and having a PCMH.

Keywords

Sickle cell disease; Health care utilization

INTRODUCTION

Children with sickle cell disease (SCD) represent a high-cost and resource intensive subgroup of children.[1,2] Innovations in basic science and clinical management have markedly improved the options for high quality SCD care.[3–9] Despite these advances,

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families still encounter multiple challenges in navigating the health care system.[10] A large body of research demonstrates that children with SCD continue to rely heavily on acute care services, [11–20] which in part, may serve as surrogates for inadequate primary care.

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.[21–25] National initiatives increasingly propose that all children, especially those with chronic conditions, have a PCMH. Studies on PCMH have demonstrated multiple benefits, including improved health outcomes, lower health care costs, increased patient satisfaction, and improved family functioning.[26,27] The American Academy of Pediatrics (AAP) currently defines a PCMH as care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.[28]

Despite the potential of a PCMH to improve the quality of care for children with SCD, little is known about the extent to which children with SCD have PCMHs as defined by the AAP. Studies regarding health care use among children with SCD have predominantly focused on acute care services.[12,14–16,29] Those examining ambulatory care have primarily examined access to hematology comprehensive care centers.[11,19] The PCMH model of primary care may have particular relevance to pediatric SCD with respect to adherence to care, collaboration with hematologists, and medical transition to adult care.

The aim of this study was to determine the extent to which children with SCD have access to care consistent with a PCMH and its specific components. Specifically, we sought to: 1) determine the degree to which children with SCD have access to PCMHs and 2) identify factors associated with having an overall PCMH or its individual components. Understanding deficiencies in the provision of PCMH care for children with SCD may provide insights into potential target areas for intervention and improvement in SCD care.

METHODS

Study Design

We conducted a cross-sectional study of access to a PCMH among children with SCD at a large children's hospital. A survey instrument was utilized to collect child and family demographic information as well as parent-reported perceptions of access to primary care. The study was approved by the Institutional Review Board of the Baylor College of Medicine, Houston, Texas. Written informed consent and child assent (when indicated) were obtained for all participants.

Participants

Participants were recruited during outpatient clinic visits at a comprehensive sickle cell center or hospitalizations within Texas Children's Hospital (TCH), a large, urban academic pediatric institution. Subjects were parents or guardians (hereafter caregivers) of children ages 1 through 17 with a diagnosis of SCD cared for at the TCH sickle cell comprehensive center for a minimum of 12 months. Eligible children had ICD-9 codes consistent with 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) caregiver inability to comprehend English. Research staff were present in the sickle cell center or rounded with the inpatient hematology service daily for 7 months. Prior to recruitment, all subjects were screened for eligibility. We attempted to recruit all subjects that were eligible for the study. Prospective caregivers were initially informed of the study by their child's provider (outpatient) or rounding team (inpatient). Those interested in participating were then formally recruited by a research coordinator. Caregivers were

asked to complete a survey instrument assessing access to a PCMH and provide consent to review of their child's medical records for the past 12 months. The participation rate among eligible families approached for the study was 77% (150/196).

Outcome Measure for PCMH

The primary outcome measure was a composite PCMH determination reflective of the AAP criteria for a PCMH. The composite was constructed from 21 questions within the 2007 National Survey of Children's Health (NSCH) intended to assess the AAP construct of a PCMH.[30] While other measures of the PCMH exist, the NSCH measure was selected for several reasons. First, it assesses multiple aspects of the medical home concept, thereby allowing examination of a wide spectrum of primary care functions. Second, there are numerous national studies published using this measure. Therefore it gives the opportunity to compare results with a substantial number of studies using the same methodology. Lastly, it has been endorsed by the National Quality Forum (NQF).[31] To qualify for NQF endorsement, a measure must meet the following criteria: 1) importance and need for reporting of measure and how it would lead to quality improvement, 2) scientific acceptability of the measurement properties; 3) usability of measure in non-tested settings; and 4) feasibility of successful replication.[32]

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.[33] 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 7 AAP PCMH attributes, 5 are operationalized in the NSCH. Continuous and accessible care are not assessed given the limitations of a point-in-time survey in measuring these components via caregiver report.

In order for a child to have a PCMH, the caregiver 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. 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?" For achieving comprehensive care, a child had to have a usual source of care for sick visits 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." 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." 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."

Independent Variables

Child covariates consisted of age, gender, insurance status, and health status. Insurance status was categorized as public versus private insurance. For describing health status, families were given the following options: poor, fair, good, very good, or excellent. For the study, we categorized health status as fair/poor versus good versus very good/excellent. In order to identify the primary care providers for all children, we used registration data from

the TCH electronic medical record. Primary care site was divided into the following categories – TCH associated primary care (TCH primary care clinic, TCH hematologist, TCH affiliated practice), non-TCH primary care, and unknown. We also included caregiver variables, including relationship to child, gender, marital status, and education. Responses for caregiver relationship to child were dichotomized as parent versus all other categories. Caregiver marital status was dichotomized as married versus other. Caregiver education was categorized as high school or less versus more than high school versus college degree.

Data Analysis

Statistical analyses were performed using SAS® 9.2 (SAS Institute Inc, Cary, NC). The PCMH composite measure was calculated from the individual PCMH components included in the survey instrument, as described above. Summary statistics were used to determine the percentage of children with SCD having access to an overall PCMH as well its individual components. Through two sets of regression analyses, we examined the associations between socio-demographic variables and having a PCMH or its individual components: (1) the PCMH outcomes were dichotomous (present/not present). Odds ratios (OR) and 95% confidence intervals (95% CI) were calculated for analyses; and (2) ordinal specification was used where the outcome was the number of medical home components achieved (0, 1, 2, 3, or 4). The ORs represent the odds of achieving a higher number of PCMH components relative to the reference group.

RESULTS

Patient and Family Demographics

Socio-demographic characteristics of our study sample are shown in Table 2. Our sample consisted of 150 children with SCD. Mean age was 9 years. Children >5–9 years of age comprised the largest age category (30.6%) in the sample. Approximately two-thirds of children were publicly insured. Less than half of children were reported to be in very good/excellent condition. In terms of caregiver characteristics, 93% of caregivers reported to be the child's parent. Over 90% of caregivers were female. A quarter of caregivers had only a high school diploma or less. Of the total population, 137 children were recruited from the sickle cell center and 13 children were recruited from the inpatient service. According to medical chart review, 51 (34%) children had TCH associated primary care, with a subset of 12 children (8% overall) listed to have a TCH hematologist as their primary care provider. Demographic data were also obtained for the 46 children whose parents refused participation in the study. No statistically significant differences were found between families who participated and those who declined.

Receipt of Care in a PCMH

Of the entire sample, only 11% (16/150) qualified as having a PCMH, achieving the required thresholds in all four components (regular provider, comprehensive care, family-centered care, and coordinated care). Achievement of cumulative components varied as follows: 4% of children did not have access to any components of a PCMH; 15% of children had access to only one component; 29% of children achieved only two components of a PCMH; and 41% of children only had access to three components of a PCMH.

There was wide variation in receiving various components of a PCMH (Table 3). Over 90% of children were reported to have a personal doctor or nurse. Two-thirds of children had access to comprehensive care. Almost 60% of children were reported to receive family centered care. Only 20% of children had access to coordinated care. Of parents who reported that their child had multiple service needs, only 30% reported that there was someone who helped coordinate their child's care. We also examined the proportion of children with SCD

who had components of a PCMH by selected socio-demographic characteristics. For having a regular provider (doctor or nurse), statistically significant differences were found according to health status and parental education. A higher proportion of children in very good/excellent health had a regular provider compared to children with fair/poor health ($p < 0.05$). A higher proportion of parents with a college degree reported that their child had a regular provider compared to parents who had a high school education or less ($p<0.05$). No statistically significant differences were found for other PCMH components according to socio-demographic variables.

Associations between Socio-demographic Variables and PCMH Components

For the overall medical home outcome, bivariate and multivariate logistic regression with the dichotomous outcome (yes/no) revealed no significant associations between socio-demographic variables and having an overall PCMH. Given the small number of children who had access to all components of a PCMH (n=16), we additionally conducted bivariate and multivariate logistic regression with ordinal specifications where the outcome was the number of PCMH components achieved. Age was the only variable to have a statistically significant relationship with the number of PCMH components achieved. Children 1–5 years of age had a lower odds (OR 0.38, 95%CI 0.16–0.88) of achieving additional components of the PCMH compared with children >5–9 years of age. Children >9–13 years of age also had a lower odds (OR 0.40, 95%CI 0.17–0.95) of achieving additional components of the PCMH compared with children >5–9 years of age. In addition to the overall PCMH, we also examined associations between socio-demographic variables and the individual components of the PCMH. No statistically significant relationships were determined.

DISCUSSION

Among a group of children with SCD, only 11% met the standards for receiving care in a PCMH. While over 90% of children had a regular doctor or nurse, they experienced deficiencies in other functions of primary care. More specifically, children with SCD often experienced inadequate comprehensive care, an absence of family centered care, and poor care coordination. These findings provide new insights on the large body of research documenting unfavorable health care utilization patterns of children with SCD with respect to emergency care use and inpatient hospitalizations.[13,14,16,18,20]

A number of national studies with identical methodology for operationalizing a PCMH and its components provide context for our findings. In a study of the general pediatric population, 57% of children had an overall medical home; 92% had a personal doctor or nurse; 67% received family-centered care; and 69% received effective care coordination when needed.[34] Reported findings were somewhat less favorable for children with chronic conditions. In a study of children with special health care needs, 47% had overall medical homes; 92% had a personal doctor or nurse; 65% received family-centered care; and 59% received effective care coordination.[35] In our study, 11% of children with SCD had an overall medical home; 91% had a personal doctor or nurse; 66% received family-centered care; and 18% received effective care coordination when needed. While these studies provide the best available comparisons, there may be differences between the subjects recruited by telephone in national surveys and our children with SCD recruited in a sickle cell center and inpatient service. Our subjects potentially had more severe disease given that they were hospitalized and receiving services in a subspecialty clinic.

Our study did not find any consistent socio-demographic variables associated with having a PCMH or its individual components. Only age was associated with the number of PCMH components achieved. Our overall negative findings with respect to associations may be attributable to our small sample size relative to large samples in national studies. Among

such studies, factors consistently associated with not having a PCMH included lower parental educational attainment, lower income, fair/poor health status, and minority race/ethnicity.[34–36] The demographic composition of children with SCD therefore puts them at high risk for failing to have a PCMH. While national surveys consistently identify children with chronic conditions such as asthma, they do not identify children with SCD. Therefore, our study fills a critical gap in the literature regarding PCMH care for children with SCD.

Our findings raise two critical issues regarding access to a PCMH for children with SCD. The first question is how primary care providers can enhance their care delivery systems to more fully meet the needs of children with SCD. While our study revealed several deficiencies in primary care for children with SCD, the lack of care coordination stood out as the most striking result. The goal of care coordination is to link children and their families with appropriate services and resources in a concentrated effort to achieve good health.[28] It may address the social, developmental, educational, and financial needs of patients and family. Care coordination has been associated with shorter hospital stays, lower costs, parental satisfaction, and stronger relationships with primary care providers.[37,38] Creating an integrated care coordination infrastructure within primary care for children with SCD may require measures of quality of care coordination specific for SCD, dedicated care coordinators, health information systems with capacity to track and monitor patients, and access to legal services.[39,40]

The second key question from our findings is whether hematologists and comprehensive sickle cell centers should assume a larger role in providing a PCMH for children with SCD. There are several arguments supporting a subspecialty practice becoming a PCMH.[41] First, a child with SCD may be seen by the hematologist frequently over a long period of time for their principal condition and it is most convenient for the hematologist practice to serve as the central hub of care. Second, the available clinical literature demonstrates that specialty physicians already address some of the primary care needs for a substantial number of patients, including care coordination.[42] In the case of SCD, hematologists may provide vaccines, address nutritional deficiencies, give guidance on development, and communicate with school systems.[43]

There are also arguments against hematology practices acting as PCMHs. Existing studies indicate that ambulatory care for children with SCD is primarily provided by primary care physicians.[44,45] Hematologists may not be located within the child's community and therefore be unable to effectively coordinate with schools and community resources. The hematologist may not be familiar with the child's family or competing needs of other family members. While some specialists provide primary care services, the quality of such care is not well studied.[46] Lastly, the willingness of hematologists to provide both principal and primary care of children with SCD is unknown. In determining whether a child with SCD should receive primary care from a hematologist or comprehensive center, several factors should be taken into consideration: convenience and proximity to a center, the relationship with the specialist at the center, the specialist's expertise and comfort in managing primary care issues, and reimbursement by the patient's insurance.

Several limitations of the study should be noted. Although endorsed by the NQF, the PCMH measure from the NSCH differs from other measures both in terms of components assessed and validation of its contents. Currently no gold standard measure of the PCMH exists. While other measures have been validated, they are limited in the scope of PCMH components measured or in survey burden attributable to survey length. Information used to determine whether a child had a PCMH as well as health status came from parent report rather than clinical sources. Therefore our data were subject to the bias inherent to this

method of data collection. In conducting logistic regression with ordinal specification, we assumed that all components of the PCMH had equal value. However, it is possible that certain components such as care coordination may be more important than others. Generalizability was limited by the method of recruitment. Hospitalized children and those needing specialty clinic services may be fundamentally different from other populations. Our sample size was small relative to national studies of children assessing access to a PCMH. Therefore we did not have the ability to detect small differences between groups and variables.

Lastly, we did not ask caregivers to specify which provider served as the reference for their survey responses. Therefore we could not determine whether caregivers were responding to questions based on their primary care experiences or those with their hematologist. However, 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. Therefore identified deficiencies in PCMH care may reflect broader gaps in co-management of care between primary and subspecialty care rather than in just one particular setting.

While the PCMH has been increasingly promoted as a potentially transformative health care delivery innovation in primary care, little is known regarding to what extent children with SCD have access to this model of care. We conclude that children with SCD in our study sample experienced multiple deficiencies in having access to a PCMH and its individual components. Our findings provide data to facilitate targeted interventions. However, caution must be exercised in drawing conclusions regarding implications for SCD quality of care given the lack of evidence demonstrating that a PCMH improves health outcomes specifically for SCD.

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Table I

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

Table II

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)
Good	53 (36.8)
Very good/Excellent	59 (41.0)
Primary Care Site	
TCH Associated Primary Care	51 (34.0)
Non-TCH Primary Care	92 (61.3)
Unknown	7 (4.7)
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)

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

Table III

Demographics According to Medical Home Components[a]

Variable	Regular Provider N(%)	Comprehensive Care N (%)	Family- Centered N (%)	Coordinated Care N(%)
All	138 (91.4)	101 (66.9)	89 (58.9)	30 (19.9)
Child Characteristics				
Age				
1–5	36 (92.3)	23 (59.0)	22 (56.4)	8 (20.5)
>5–9	45 (97.8)	34 (73.9)	34 (73.9)	12 (26.1)
>9–13	32 (86.5)	27 (73.0)	18 (48.7)	6 (16.2)
>13–17	25 (89.3)	17 (60.7)	15 (53.6)	4 (14.3)
Gender				
Male	73 (92.4)	48 (60.8)	48 (60.8)	17 (21.3)
Female	65 (91.6)	53 (74.7)	41 (57.8)	13 (18.3)
Insurance				
Public	87 (92.6)	65 (69.2)	54 (57.5)	18 (19.2)
Private	46 (97.9)	32 (68.1)	33 (70.2)	12 (25.5)
Health Status				
Fair/Poor	27 (84.4)	22 (68.8)	21 (65.6)	4 (12.5)
Good	52 (98.1)	34 (64.2)	33 (62.3)	12 (22.6)
Very good/Excellent	57 (96.6)	43 (72.9)	34 (57.6)	14 (20.8)
Primary Care Site				
TCH	45 (88.2)	35 (68.6)	28 (54.9)	9 (17.6)
Non-TCH	86 (93.5)	61 (66.3)	59 (64.1)	21 (22.8)
Unknown	7 (100)	5 (71.4)	2 (28.6)	0 (0.0)
Caregiver Characteristics				
Relationship to Child				
Parent	128 (94.1)	97 (71.3)	81 (59.6)	26 (19.1)
Other	10 (100)	4 (40.0)	8 (80.0)	4 (40.0)
Gender				
Female	125 (94.0)	92 (69.2)	81 (60.9)	26 (19.6)
Male	12 (100)	8 (66.7)	7 (58.3)	3 (25.0)
Marital Status				
Married	57 (95.0)	43 (71.7)	38 (63.3)	18 (30.0)
Other	81 (94.2)	58 (67.4)	51 (59.3)	12 (14.0)
Education				
High school or less	31 (88.6)	29 (82.9)	16 (45.7)	7 (20.0)
More than high school	54 (93.1)	36 (62.1)	39 (67.2)	10 (17.2)
College Degree	53 (100)	36 (67.9)	34 (64.2)	13 (24.5)

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