Association of Care in a Medical Home and Health Care Utilization Among Children with Sickle Cell Disease

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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, aged 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.

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 τ 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 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