Title

Association between hospital admissions and healthcare provider communication for individuals with sickle cell disease

Journal

Hematology, 25(1)

ISSN

1024-5332

Authors

Cronin, Robert M
Yang, Manshu
Hankins, Jane S
et al.

Publication Date

2020

DOI

10.1080/16078454.2020.1780737

Published in final edited form as:
Hematology. 2020 December ; 25(1): 229–240. doi:10.1080/16078454.2020.1780737.

Association between hospital admissions and healthcare provider communication for individuals with sickle cell disease

Robert M Cronin, MD, MS[1,2,3], **Manshu Yang, PhD**[4,5], **Jane S Hankins, MD, MS**[6], **Jeannie Byrd, RN, MSN**[7], **Brandi M Pernell, DNP, PNP-BC**[7,8], **Adetola Kassim, MD**[9], **Patricia Adams-Graves, MD**[10], **Alexis A. Thompson, MD, MPH**[11], **Karen Kalinyak, MD**[12], **Michael DeBaun, MD, MPH**[7], **Marsha Treadwell, PhD**[13]

[1]Department of Biomedical Informatics, Vanderbilt University Medical Center, Nashville, TN, 37203

[2]Department of Internal Medicine, Vanderbilt University Medical Center, Nashville, TN, 37232

[3]Department of Pediatrics, Vanderbilt University Medical Center, Nashville, TN, 37232

[4]Department of Psychology, University of Rhode Island, Kingston, RI, 02879

[5]American Institutes for Research, Chapel Hill, NC, 27514

[6]Department of Hematology, St Jude Children's Research Hospital, Memphis, TN, 38105

[7]Department of Pediatrics, Division of Hematology/Oncology, Vanderbilt-Meharry Center for Excellence in Sickle Cell Disease, Vanderbilt University Medical Center, Nashville, TN, 37232

[8]University of Alabama at Birmingham, Department of Pediatrics, Division of Hematology, Birmingham, AL, 35294

[9]Department of Hematology/Oncology, Vanderbilt University Medical Center, Nashville, TN, 37232

[10]Department of General Internal Medicine and Hematology, University of Tennessee Health Science Center, Memphis, TN, 38163

[11]Department of Pediatrics, Department of Medicine, Northwestern University, Chicago, IL, 60611

[12]Division of Hematology in Cancer and Blood Diseases Institute, University of Cincinnati, Cincinnati, OH, 45229

[13]Department of Hematology/Oncology, UCSF Benioff Children's Hospital Oakland, Oakland, CA, 94609

Abstract

Corresponding Author: Robert M Cronin, MD, MS, 2525 West End, Suite 1475, Nashville, TN 37203, Phone: 615-936-5097, Fax: 615-936-0102, robert.cronin@vumc.org.

Contributors: JSH, BMP, AAK, PA, AAT, KK, MRD, and MT conceived the study design. All authors contributed in data collection. MY, RMC and MT performed data analysis and interpretation of the results. All authors contributed to the writing and review of the manuscript.

Ethical approval: The Institutional Review Boards of the participating sites approved all study procedures and informed consent was obtained from all participants.

Data sharing: De-identified data are available upon request from the corresponding author.

Objective: To test the hypothesis that caregivers' or adult participants' low ratings of provider communication are associated with more hospital admissions among adults and children with sickle cell disease (SCD), respectively. Secondarily, we determined whether there was an association between the caregivers' or participants' health literacy and rating of providers' communication.

Methods: Primary data were collected from participants through surveys between 2014–2016, across six sickle cell centers throughout the U.S. In this cross-sectional cohort study, 211 adults with SCD and 331 caregivers of children with SCD completed surveys evaluating provider communication using the Consumer Assessment of Healthcare Providers and Systems (CAHPS), healthcare utilization, health literacy, and other sociodemographic and behavioral variables. Analyses included descriptive statistics, bivariate analyses, and logistic regression.

Results: Participants with better ratings of provider communication were less likely to be hospitalized (odds ratio (OR) = 0.54, 95% confidence interval (CI) = [0.35, 0.83]). Positive ratings of provider communication were associated with fewer readmissions for children (OR = 0.23, 95% CI = [0.09, 0.57]). Participants with better ratings of provider communication were less likely to rate their health literacy as lower (regression coefficient (B) = −0.28, 95% CI = [−0.46, −0.10]).

Conclusions: Low ratings of provider communication were associated with more hospitalizations and readmissions in SCD, suggesting the need for interventions targeted at improving patient-provider communication which could decrease hospitalizations for this population.

Keywords

provider communication; shared decision-making; vulnerable populations; health care surveys; sickle cell anemia; Consumer Assessment of Healthcare Providers and Systems

INTRODUCTION

Sickle cell disease (SCD) is a hereditary disorder of hemoglobin within the red blood cells, affecting over 100,000 Americans, many of whom face health disparities[1–4]. With improvements in care, SCD has become a chronic disease that affects both children and adults[5]. Despite improvements in SCD management, significant challenges persist, including a significant burden of hospitalizations[4,6–9], costs over $900,000 by the age of 45 years[10], poor adherence to preventive care, including missing appointments[11–17], and lack of providers with knowledge and expertise in the disease[18–20]. A poor provider-patient relationship, an important indicator of patient experience and healthcare quality, can contribute to these challenges. Inadequate provider communication has been shown to lead to unfavorable outcomes in other diseases such as high blood pressure, anxiety, pain in postoperative situations, and problem and symptom resolution[21,22].

Literature focusing on the provider-patient relationship in SCD is sparse, and only in adults[23–25]. In 2009, Haywood et al. evaluated ratings between provider communication with sociodemographic factors and levels of trust in the medical profession. This study was done among adults with SCD at a single center and demonstrated that better ratings of provider communication were associated with older patient age, lower household income, and less frequent hospital utilization. The researchers also showed that lower ratings of provider communication were associated with lower levels of trust towards the medical profession. In 2014, Haywood et al. performed a multi-center study to compare the proportion of individuals with SCD that rated their provider communication as poor as compared to a U.S. sample of African American adult patients. Their study revealed that individuals with SCD rated provider communication as poor significantly more often than the national sample of African Americans. They also demonstrated that younger individuals with SCD and those with a higher education were more likely to rate their communication with their provider lower than similar individuals from the national sample. Prior studies that investigated provider communication only included adults with SCD, and only one evaluated associations with social determinants of health[23–25].

The present multi-center study of individuals with SCD across the U.S. tested the hypothesis that poor perceived provider communication is associated with increased hospitalizations in children and adults with SCD. The study was part of the Mid-South Clinical Data Research Network (CDRN)[26], which enrolled thousands of participants with different chronic diseases. We used two psychometrically validated composites from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) to measure provider communication and shared decision-making[27–32]. We evaluated provider-patient communication within the framework of other contextual factors, such as social and behavioral determinants of health, given the high burden of social determinants of health in SCD and the influence of these factors on health utilization and outcomes[33,34].

METHODS

This project was part of the Mid-South CDRN[26], funded by the Patient-Centered Outcomes Research Institute (PCORI). The Mid-South CDRN survey tool was designed to obtain uniform information across cohorts with obesity, coronary heart disease and SCD. The Institutional Review Boards of the participating sites approved all study procedures and informed consent was obtained from all participants.

Setting and Procedure

Between October 2014 and March 2016, we surveyed a convenience sample of adults with SCD (patients age ≥18 years) and caregivers of children with SCD (patients age < 18 years). Six sickle cell centers across the U.S. participated: Cincinnati Children’s Hospital Medical Center, Lurie Children’s Hospital of Chicago, University of Tennessee Health Science Center, St. Jude Children’s Research Hospital, Vanderbilt University Medical Center, and the University of California San Francisco Benioff Children’s Hospital Oakland. Survey participant inclusion criteria included: 1) ability to speak and read English, 2) received care at one of the six contributing centers, and 3) had a diagnosis of SCD (of any phenotype) or were parents/caregivers of children with SCD. Individuals with SCD and their caregivers were recruited either by their health care providers during clinic visits or by using flyers in clinics. Participants completed surveys on computer tablets, or by paper-and-pencil. Members of the research team were present for questions. Participants’ time was compensated with a gift card upon completion of the survey.

Surveys

The full details of the surveys are described elsewhere[9,35], but are briefly described here. Various stakeholders, including individuals with SCD, helped design the survey tools and selected the final questions. Question domains included patient-reported healthcare experience (e.g., provider communication, shared decision-making), perceived health literacy, healthcare utilization (e.g., hospitalizations, readmissions and clinic appointment adherence), and social and behavioral determinants of health. We combined some categories of survey responses for ease of interpretation within the regression analyses. Caregivers responded about themselves for educational attainment, difficulty paying bills, and marital status, and answered about their child for the other questions.

Healthcare experience – CAHPS measures—In this study, we evaluated perceived provider communication which encompasses the ability of the provider to gather information to facilitate accurate diagnosis, counsel appropriately, give therapeutic instructions, and establish caring relationships with their patients[36]. We selected four questions related to *provider communication* from the CAHPS Clinician & Group Survey Version 3.0[37], using a 4-point scale from “Never” (1) to “Always” (4). The surveys cover topics such as how well providers communicate with their patients, provide care, and the helpfulness of staff, all important topics to patients and for which patients are the best information source. The four questions we selected were: did your provider (1) explain things in a way that was easy to understand, (2) listen carefully to you, (3) show respect for what you had to say, and (4) spend enough time with you or your child. CAHPS surveys are widely used and extensively validated measurement tools to elicit patient reports about their healthcare experiences. Shared decision making (SDM) has been defined as: “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences[38].” We selected two questions about *shared decision-making* based on the three relevant items in the CAHPS Patient-Centered Medical Home Survey[30] - (1) did your provider talk with you about the pros and cons of each choice for treatment or health care and (2) did your provider ask which choice you thought was best for you or your child, answered on a 4-point scale from “Definitely yes” (1) to “Definitely no” (4). For each of the two CAHPS domains, *provider communication* and *shared decision-making*, a composite score for each respondent was computed by averaging the individual item responses within a domain. Composite scores were calculated if at least half of the items in a domain were answered.

Health Literacy – Brief Health Literacy Screening—Health literacy, or the ability to understand, communicate, and act on health information, was evaluated using the Brief Health Literacy Screening[39,40]. Inadequate health literacy can be determined from one or a combination of all three of these questions[39,40]. Responses of “somewhat” or better for the question “How confident are you filling out medical forms by yourself?” has been used to define “good” health literacy[39]. Caregivers responded about their health literacy, not their child’s.

Social and behavioral determinants of health—Depressive symptoms were measured by the Patient Health Questionnaire (PHQ-2[41]), Participants rated their social supports using the ENRICHD (Enhancing Recovery in Coronary Heart Disease) Social Support Inventory (ESSI[42]). Low support has been defined as 2 or more items ≤2, or 2 or more items ≤3 and an adjusted overall score ≤18[43]. Participants and caregivers rated spirituality using a single item "how spiritual or religious do you consider yourself (or your child) to be," from very (1) to not at all (4). Based on the distribution of the responses and for ease of analysis, we dichotomized the variable into "very" spiritual (option 1) and "not very" spiritual (options 2–4). Social determinants of health included sex, race, ethnicity, educational attainment, difficulty paying bills, and marital status.

Healthcare utilization – missed clinic appointments, hospitalizations, and readmissions—Adults with SCD and caregivers of children self-reported missed clinic appointments, hospitalizations, and readmissions within the past year. Readmissions were defined as being admitted to the hospital twice in a 30-day period.

Statistical Analysis

Study data were collected, de-identified, and managed using the REDCap electronic data capture tools hosted at Vanderbilt University[44]. Surveys were excluded from analyses for missing data about age, site, and sex. We first used descriptive statistics to summarize demographics, social and behavioral determinants of health, and other questions. Means, standard deviations, and ranges were used for continuous variables, medians and ranges for count variables, and frequencies and proportions for categorical variables. Next, we reported descriptive statistics (mean, standard deviation, and frequency distribution) for the CAHPS items and conducted confirmatory factor analysis (CFA) to examine if the six items could be grouped into the two composites, provider communication and shared decision making, as hypothesized.

We explored bivariate associations among provider communication, shared decision-making, and potential risk factors, i.e., social determinants of health (sex, age, race, ethnicity, education level, marital status, household size, ability to pay bills), depressive symptoms, health literacy, social support, and spirituality. Bivariate associations were examined using either Pearson correlation or t-test as appropriate. We created logistic regression models for the outcome measure of hospital admissions, readmissions, and missed appointments. We also created linear regression models using each of the three health literacy items as outcome measures. In each regression model, provider communication, shared decision-making, and all the risk factors were included as predictors. Initially, models were created for all participants but given that adults and children with SCD have important differences in outcome measures, we also conducted regression analyses for adults and children separately. For binary outcomes (i.e., hospital admission, readmission, and missed appointment), race and ethnicity were not included as predictors in the regression models because there were too few non-African American or Hispanic participants when examining adults and children with SCD separately. Given that 14% of respondents (only 2% among adults but 21% among caregivers of children) did not report their education level, we considered missing education level as a valid response category in order to retain a larger sample size when conducting analyses in the full sample and in the pediatric patient sample. We excluded such cases in the regression models for adult patients, given the small proportion (2%) of missing data.

CFA was conducted using Mplus version 8[45], and all other analyses were performed in SAS version 9.2[46]. P-values were considered significant if < 0.05[47].

RESULTS

Demographics

A total of 573 individuals with SCD (adults and caregivers of children with SCD) completed the surveys at a single clinic visit. After excluding surveys with missing data, our final sample for analysis included 211 adults with SCD and 331 caregivers of children with SCD (n= 542). We oversampled our population to accommodate nonresponses and exceeded our projected sample size of 450. Table 1 shows the distribution of socio-demographic characteristics and summarizes scores for depressive symptoms, social support, and health literacy for adults and pediatric patients.

Socio-demographic variables vary among adults with SCD and children with SCD (as reported by their caregivers).—Forty-five percent of the total sample reported it was “somewhat” to “very difficult” to pay monthly bills. About 42% of the total sample rated themselves as “very” spiritual or religious. Most adults and caregivers rated their health literacy as “good” (75%). The mean score on the PHQ-2 for depression in adults (1.46, SD=1.55) was higher than what caregivers reported for children (0.84, SD=1.26). This is very similar to what we previously reported[9].

Patient-reported experiences about provider communication were positive.— As shown in Table 2, the majority (74% to 85%) of the total sample answered “Always” to the four items about provider communication. About 63% of respondents reported “Definitely yes” to the two items about shared decision-making.

Hypothesized composite structure for provider communication and shared decision- making fit well.—The two-factor CFA model showed excellent model fit, with the Root Mean Squared Error of Approximation (RMSEA) = 0.031, Comparative Fit Index (CFI) = 0.999, and Tucker-Lewis Index (TLI) = 0.999, suggesting that the measures have good construct validity and composite scores should be computed as planned. An RMSEA < 0.06, a CFI > 0.95, and a TLI > 0.95 indicate good fit[48–50]. The factor loading of the six items on the two factors (domains) is shown in Table 2.

Better experience of provider communication was associated with a lower likelihood of hospital admission and readmission as well as fewer problems reported by patients with learning about their medical conditions.—Bivariate associations among provider communication, shared decision making, and patient characteristics are shown in Supplementary Tables 1 and 2. Better experience with provider communication was associated with higher level of shared decision-making ($p < 0.0001$) and better social support (mean difference of provider communication score = 0.15, 95% confidence interval (CI) = [0.04, 0.27]). Female patients reported better experience with shared decision-making than males (mean difference = 3.32, 95% CI = [0.08, 0.38]). Results from regression analyses are shown in Tables 3 and 4.

In the full sample, patients with better experience of provider communication were less likely to be hospitalized (odds ratio (OR) = 0.54, 95% CI = [0.35, 0.83]). When analyzed separately, the result was not statistically significant for adult patients but still held true for children with SCD (OR = 0.54, 95% CI = [0.31, 0.94]). Hospital readmission was not associated with provider communication or shared decision-making in the full sample. However, among children with SCD, patients whose caregivers had better experience of provider communication were less likely to have readmissions (OR = 0.23, 95% CI = [0.09, 0.57]) while those with better experience of shared decision-making were more likely to have readmissions (OR = 2.38, 95% CI = [1.04, 5.43]). Neither provider communication nor shared decision-making were significantly associated with the likelihood of missing appointments. Regarding health literacy, for the full sample, patients/caregivers with better experience of provider communication were less likely to have problems learning about their medical conditions because of difficulty understanding written information (regression coefficient (B) = −0.28, 95% CI = [−0.46, −0.10]). When children and caregivers were analyzed separately, this result held true among adults (B = −0.36, 95% CI = [−0.70, −0.02]) but not among caregivers of children with SCD.

DISCUSSION

Our manuscript is one of the first to leverage a national research network of sickle cell centers to describe the relationship between patient experience (i.e. provider communication and shared decision making) and acute healthcare utilization (i.e., hospitalizations, readmissions, and missed appointments) in children and adults with SCD. Poor provider communication, as experienced by caregivers of children, was a significant predictor of higher hospitalizations and readmissions; however, these significant associations were not seen in adults. The reason we may see this difference in findings is that caregivers are usually at a heightened level of vigilance and anxiety, poor communication and relationship with providers may make them go to hospital more often when they see even a small sign of discomfort in their children. Adult patients, on the other hand, might be more experienced with SCD self-management and less likely to go to hospital even when their communication with providers is not as good. Also, there are differences between these two populations, including other potentially important factors that might contribute to making healthcare provider communication not significant in relation to healthcare utilization for adults. These might include a lack of primary care providers, mental health issues, and financial hardship which are all more prevalent in the adult population[9,51]. In addition, while not statistically significant, the odds ratio for both adults and pediatrics were similar (pediatrics: 0.54 vs adults: 0.57). The lack of significance could be because of our smaller sample size of adults (pediatric: 330 vs. adults: 175). Provider communication may become a significant predictor if we had a larger sample of adults with SCD. Further research is needed on these differences. These findings are novel, have not been well described in the literature in any chronic diseases, and demonstrate the importance of good provider communication as experienced by patients and their caregivers in decreasing acute healthcare utilization. These findings demonstrate a need for interventions that are focused on improving poor patient-provider communication.

Paradoxically, children demonstrated lower healthcare utilization when their caregivers experienced poor shared decision-making with their providers. One potential reason for this finding is that there are inevitable reasons for hospitalization in children with SCD (e.g., fevers). Children with SCD with fevers can develop blood infections and sepsis and need to be monitored closely and given proper interventions. Caregivers who perceive that they can participate in good shared decision making with their providers may feel enabled to seek early interventions This may lead to increased hospitalization but prevents significant morbidity and mortality that can happen with delayed treatment. Others have shown that better disease knowledge is associated with higher healthcare utilization in children with SCD[52], and it is conceivable that better knowledge and shared decision-making yield a more activated caregiver who ends up at the hospital more often.

In our secondary analyses of patient experience and health literacy as associated with missed appointments, we found mixed results. Adults with better experience of provider communication were less likely to have problems learning about their medical conditions because of difficulty understanding written information. Having better health literacy could mean a better ability to assimilate the content of the provider communication. Shared decision-making was not significantly associated with health literacy. Neither provider communication nor shared decision-making were significantly associated with missed appointments. In our prior work, we found that “forgetting”, “time not working” and “not having transportation” were the most likely reasons for missing appointments[17]. These reasons for missed appointments would not likely be affected by poor provider communication or shared decision making.

Shared decision-making and provider communication were positive and comparable to a national benchmark[53]. Our results in the provider communication domain were comparable to the percentages of responding “Always” (79% to 87%) to the provider communication questions (Table 2) reported in the 2016 national benchmark sample of the CAHPS Clinician & Group Adult Survey[53]. For shared decision-making, while positive, the percentage of responding “Definitely yes” to the shared decision making questions (Table 2) had more variation among the three items in the 2016 national benchmark sample (range, 43% to 80%) than the two items in our survey (both approximately 63%). Since the questions in our survey were somewhat different from those in the CAHPS PCMH (Patient Centered Medical Home) item set, results were not quite comparable. In our survey, two shared decision-making items from the CAHPS PCMH item set (i.e., “provider talked about reasons to take a medicine” and “provider talked about reasons not to take a medicine”) were combined into one item named “provider talked about the pros and cons of each choice”. In addition, unlike in the CAHPS PCMH item set, respondents were not asked to skip the shared decision-making items in our survey if they previously reported that providers did not tell them that they had more than one choice for their (or their child’s) treatment.

Certain limitations caution interpretation of our study findings. First, there can be recall bias from patient-reported healthcare utilization. While there may be difficulty recalling hospitalizations, these are disruptive events that people are more likely to remember. Better evaluation of the accuracy of self-reported hospitalizations as compared to electronic health record data is an area of future research. Interventions that are focused on improving poor patient-provider communication should be dependent on more precise data to support conclusions. Also, missing appointments were self-reported and likely under-reported by some participants, which may impact the associations between missing appointments and other variables, such as health literacy and provider communication. Second, while selection bias may have occurred from our convenience sample of participants who attended outpatient clinic visits, our participants were approached sequentially, without any selection for disease severity or social factors. The participants in this study are also from a sample that have a pattern of established outpatient care. There is a subpopulation of adults who are high utilizers who rarely, if ever, are seen in an outpatient setting. Further research including this population is needed. Third, there may be concerns of external validity as responses may differ in other areas of the U.S. that were not sampled. Fourth, caregivers may have answered questions about themselves or the child patient inappropriately. However, research personnel who administered the surveys did not feel there was confusion about whom the questions were concerned with. Fifth, the wording of the questions asked in our survey was modified from the original shared decision-making domain of CAHPS, which may limit interpretation of these findings. Sixth, we were unable to assess disease severity. This can be a very important factor for perceptions about provider communication. Disease severity is an area of current SCD research as genotype does not always predict severity of sequelae, but is an important component that will need to be considered when evaluating provider communication[54]. Seventh, there is a possibility of response bias. Research coordinators were the ones primarily responsible for providing participants with tablets or paper-and-pencil versions of the survey and remained available for questions. In a very few cases, participants may have been handed a tablet by a member of the healthcare team. However, the survey was self-administered and not completed through an interview with the research or clinical staff. The informed consent form contained language that responses to the survey would not have impact on healthcare benefits received. All of this would limit some biases like social-desirability bias but may lead to other biases[55]. Finally, other factors for which data were not collected (e.g., insurance coverage) could have contributed to admissions and readmissions and may have affected the significant relationships found with patient experience predictors. However, provider communication could be the root cause of many mediators (e.g., medication adherence, outpatient follow-up) and could ultimately lead to hospitalization. We were unable to test this pathway based on our available data. Future research would include a longitudinal study where the predictor (provider communication), mediators, and the outcome (hospitalization) are measured over time. Evaluating associations of communication with rates of patient adherence in other areas of their care such as filling prescriptions and taking medications would be interesting. Future research might also subsequently focus on developing an intervention to improve provider communication, then evaluate the causal relationship between provider communication and hospitalizations. Due to our cross-sectional survey data, we cannot fully exclude the possibility that our findings represent coincidental correlations, but the current study, unique in its focus on provider communication and patient/family experiences across the lifespan in SCD, lays the foundation for future research.

CONCLUSIONS

Our results highlight that provider communication can be a powerful factor in predicting hospitalizations and readmissions. Interventions are needed to help improve patient-provider communication. These interventions have the potential to decrease costly hospitalizations and readmissions in SCD and could potentially translate to lowering acute healthcare utilization in other chronic diseases. Future research evaluating patient-provider communication in chronic diseases can improve our understanding of this important concept and how it affects healthcare utilization, morbidity, and mortality.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWELDGMENTS:

The authors want to thank the members of the Vanderbilt-Meharry Center of Excellence in Sickle Cell Disease for assisting in manuscript review; Bertha Davis assisting with regulatory matters; Brittany L. Myers, DNP, RN assisting with recruiting patients; and Natasha Dean for her help in manuscript preparation. The authors also thank the individuals with SCD and their caregivers who participated in this study.

Funding: This work was supported by PCORI Grant Number CDRN 1501-26498 and research reported in this publication was supported by the National Heart, Lung, And Blood Institute of the National Institutes of Health under Award Number K23HL141447.

REFERENCES

1. Brousseau DC, Panepinto JA, Nimmer M, Hoffmann RG. The number of people with sickle-cell disease in the United States: national and state estimates. Am J Hematol. 2010;85(1):77–78. [PubMed: 20029951]
2. Mvundura M, Amendah D, Kavanagh PL, Sprinz PG, Grosse SD. Health care utilization and expenditures for privately and publicly insured children with sickle cell disease in the United States. Pediatric blood & cancer. 2009;53(4):642–646. [PubMed: 19492318]
3. Steiner CA, Miller JL. Sickle cell disease patients in US hospitals, 2004. 2006.
4. Yusuf HR, Atrash HK, Grosse SD, Parker CS, Grant AM. Emergency department visits made by patients with sickle cell disease: a descriptive study, 1999–2007. Am J Prev Med. 2010;38(4 Suppl):S536–541. [PubMed: 20331955]
5. Chaturvedi S, DeBaun MR. Evolution of sickle cell disease from a life-threatening disease of children to a chronic disease of adults: The last 40 years. Am J Hematol. 2016;91(1):5–14. [PubMed: 26547630]
6. Dunlop RJ, Bennett KC. Pain management for sickle cell disease. Cochrane Database Syst Rev. 2006(2):CD003350. [PubMed: 16625580]
7. Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. JAMA. 2010;303(13):1288–1294. [PubMed: 20371788]
8. Aljuburi G, Laverty AA, Green SA, et al. Trends in hospital admissions for sickle cell disease in England, 2001/02–2009/10. J Public Health (Oxf). 2012;34(4):570–576. [PubMed: 22653886]
9. Cronin RM, Hankins JS, Byrd J, et al. Risk factors for hospitalizations and readmissions among individuals with sickle cell disease: results of a U.S. survey study. Hematology. 2019;24(1):189–198. [PubMed: 30479187]
10. Kauf TL, Coates TD, Huazhi L, Mody-Patel N, Hartzema AG. The cost of health care for children and adults with sickle cell disease. Am J Hematol. 2009;84(6):323–327. [PubMed: 19358302]

11. Brandow AM, Panepinto JA. Hydroxyurea use in sickle cell disease: the battle with low prescription rates, poor patient compliance and fears of toxicities. Expert review of hematology. 2010;3(3):255–260. [PubMed: 21082977]
12. Ware RE, Aygun B. Advances in the use of hydroxyurea. ASH Education Program Book. 2009;2009(1):62–69.
13. Hassell KL. Provider barriers to hydroxyurea use in adults with sickle cell disease: a survey of the Sickle Cell Disease Adult Provider Network. Journal of the National Medical Association. 2008;100(8):968–974. [PubMed: 18717150]
14. Candrilli SD, O'brien SH, Ware RE, Nahata MC, Seiber EE, Balkrishnan R. Hydroxyurea adherence and associated outcomes among Medicaid enrollees with sickle cell disease. American journal of hematology. 2011;86(3):273–277. [PubMed: 21328441]
15. Raphael JL, Shetty PB, Liu H, Mahoney DH, Mueller BU. A critical assessment of transcranial doppler screening rates in a large pediatric sickle cell center: opportunities to improve healthcare quality. Pediatric blood & cancer. 2008;51(5):647–651. [PubMed: 18623200]
16. Beverung LM, Brousseau D, Hoffmann RG, Yan K, Panepinto JA. Ambulatory quality indicators to prevent infection in sickle cell disease. American journal of hematology. 2014;89(3):256–260. [PubMed: 24779032]
17. Cronin RM, Hankins JS, Byrd J, et al. Modifying factors of the health belief model associated with missed clinic appointments among individuals with sickle cell disease. Hematology. 2018:1–9.
18. Haywood C Jr., Beach MC, Lanzkron S, et al. A systematic review of barriers and interventions to improve appropriate use of therapies for sickle cell disease. Journal of the National Medical Association. 2009;101(10):1022–1033. [PubMed: 19860302]
19. Jordan L, Swerdlow P, Coates TD. Systematic review of transition from adolescent to adult care in patients with sickle cell disease. Journal of pediatric hematology/oncology. 2013;35(3):165–169. [PubMed: 23511487]
20. Yawn BP, Buchanan GR, Afenyi-Annan AN, et al. Management of sickle cell disease: summary of the 2014 evidence-based report by expert panel members. JAMA. 2014;312(10):1033–1048. [PubMed: 25203083]
21. Ashton CM, Haidet P, Paterniti DA, et al. Racial and ethnic disparities in the use of health services: bias, preferences, or poor communication? Journal of general internal medicine. 2003;18(2):146–152. [PubMed: 12542590]
22. Stewart M, Brown JB, Boon H, Galajda J, Meredith L, Sangster M. Evidence on patient-doctor communication. Cancer. 1999;25(1999):30.
23. Evensen CT, Treadwell MJ, Keller S, et al. Quality of care in sickle cell disease: Cross-sectional study and development of a measure for adults reporting on ambulatory and emergency department care. Medicine. 2016;95(35):e4528. [PubMed: 27583862]
24. Haywood C Jr., Bediako S, Lanzkron S, et al. An unequal burden: poor patient-provider communication and sickle cell disease. Patient education and counseling. 2014;96(2):159–164. [PubMed: 24935607]
25. Haywood C Jr., Lanzkron S, Ratanawongsa N, et al. The association of provider communication with trust among adults with sickle cell disease. J Gen Intern Med. 2010;25(6):543–548. [PubMed: 20195785]
26. Rosenbloom ST, Harris P, Pulley J, et al. The Mid-South clinical Data Research Network. J Am Med Inform Assoc. 2014;21(4):627–632. [PubMed: 24821742]
27. Dyer N, Sorra JS, Smith SA, Cleary PD, Hays RD. Psychometric properties of the Consumer Assessment of Healthcare Providers and Systems (CAHPS(R)) Clinician and Group Adult Visit Survey. Medical care. 2012;50 Suppl:S28–34. [PubMed: 23064274]
28. Hays RD, Berman LJ, Kanter MH, et al. Evaluating the psychometric properties of the CAHPS Patient-centered Medical Home survey. Clinical therapeutics. 2014;36(5):689–696.e681. [PubMed: 24811752]
29. Levinson W, Lesser CS, Epstein RM. Developing physician communication skills for patient-centered care. Health Aff (Millwood). 2010;29(7):1310–1318. [PubMed: 20606179]
30. Scholle SH, Vuong O, Ding L, et al. Development of and field test results for the CAHPS PCMH Survey. Medical care. 2012;50 Suppl:S2–10. [PubMed: 23064272]

31. Tsai TC, Orav EJ, Jha AK. Patient satisfaction and quality of surgical care in US hospitals. Annals of surgery. 2015;261(1):2–8. [PubMed: 24887985]
32. Weidmer BA, Brach C, Hays RD. Development and evaluation of CAHPS survey items assessing how well healthcare providers address health literacy. Medical care. 2012;50(9 Suppl 2):S3–11.
33. Power-Hays A, Li S, Mensah A, Sobota A. Universal screening for social determinants of health in pediatric sickle cell disease: A quality-improvement initiative. Pediatr Blood Cancer. 2019:e28006. [PubMed: 31571379]
34. Tewari S, Brousse V, Piel FB, Menzel S, Rees DC. Environmental determinants of severity in sickle cell disease. Haematologica. 2015;100(9):1108–1116. [PubMed: 26341524]
35. Cronin RM, Hankins JS, Adams-Graves P, et al. Barriers and facilitators to research participation among adults, and parents of children with sickle cell disease: A trans-regional survey. Am J Hematol. 2016;91(10):E461–462. [PubMed: 27421796]
36. Duffy FD, Gordon GH, Whelan G, et al. Assessing competence in communication and interpersonal skills: the Kalamazoo II report. Acad Med. 2004;79(6):495–507. [PubMed: 15165967]
37. Ahrq. CAHPS Clinician and Group Survey Measures | Agency for Healthcare Research & Quality. https://www.ahrq.gov/cahps/surveys-guidance/cg/about/survey-measures.html. Published 2016. Updated 2016-05-18 Accessed August 8, 2019, 2019.
38. Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. Bmj. 2010;341:c5146. [PubMed: 20947577]
39. Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. Journal of general internal medicine. 2008;23(5):561–566. [PubMed: 18335281]
40. Wallace LS, Rogers ES, Roskos SE, Holiday DB, Weiss BD. Brief report: screening items to identify patients with limited health literacy skills. J Gen Intern Med. 2006;21(8):874–877. [PubMed: 16881950]
41. Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: validity of a two-item depression screener. Medical care. 2003;41(11):1284–1292. [PubMed: 14583691]
42. Vaglio J Jr., Conard M, Poston WS, et al. Testing the performance of the ENRICHD Social Support Instrument in cardiac patients. Health Qual Life Outcomes. 2004;2:24. [PubMed: 15142277]
43. Berkman LF, Blumenthal J, Burg M, et al. Effects of treating depression and low perceived social support on clinical events after myocardial infarction: the Enhancing Recovery in Coronary Heart Disease Patients (ENRICHD) Randomized Trial. JAMA: Journal of the American Medical Association. 2003.
44. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42(2):377–381. [PubMed: 18929686]
45. Muthén L, Muthén B. Mplus. The comprehensive modelling program for applied researchers: user’s guide. 2019;5.
46. Institute S. SAS user’s guide: statistics. Vol 2: Sas Inst; 1985.
47. Team RC. R: A language and environment for statistical computing. R foundation for Statistical Computing 2005.
48. Browne MW, Cudeck R. Alternative ways of assessing model fit. Sage focus editions. 1993;154:136–136.
49. Tucker LR, Lewis C. A reliability coefficient for maximum likelihood factor analysis. Psychometrika. 1973;38(1):1–10.
50. Bentler PM. Comparative fit indexes in structural models. Psychological bulletin. 1990;107(2):238. [PubMed: 2320703]
51. Brodsky MA, Rodeghier M, Sanger M, et al. Risk Factors for 30-Day Readmission in Adults with Sickle Cell Disease. The American journal of medicine. 2017;130(5):601 e609–601 e615.
52. Carden MA, Newlin J, Smith W, Sisler I. Health literacy and disease-specific knowledge of caregivers for children with sickle cell disease. Pediatr Hematol Oncol. 2016;33(2):121–133. [PubMed: 26934177]

53. Ahrq. About CG Database | The CAHPS Database. https://cahpsdatabase.ahrq.gov/CAHPSIDB/CG/about.aspx. Published 2016. Accessed August 8, 2019, 2019.

54. Quinn CT. Minireview: Clinical severity in sickle cell disease: the challenges of definition and prognostication. Exp Biol Med (Maywood). 2016;241(7):679–688. [PubMed: 27013545]

55. Bowling A Mode of questionnaire administration can have serious effects on data quality. Journal of Public Health. 2005;27(3):281–291. [PubMed: 15870099]

Table 1:

Socio-demographics and standard measures for participants with sickle cell disease

Variable		Combined (N=542)	Adults (N=211)	Children[a] (N=331)
Age (Years)	Mean (SD, Range)	17.9 (13.2, 0–70)	30.7 (12.1, 18–70)	9.8 (4.6, 0–17)
Sex	Male	252 (46.5%)[b]	91 (43.1%)	161 (48.6%)
	Female	290 (53.5%)	120 (56.9%)	170 (51.4%)
Race/Ethnicity	Black, African American, African, or Afro-Caribbean	527 (97.2%)	203 (96.2%)	324 (97.9%)
	Hispanic, Latino, or Spanish origin	10 (1.9%)	5 (2.4%)	5 (1.5%)
	Some other race or origin	19 (3.5%)	10 (4.7%)	9 (2.7%)
Highest degree or level of school completed	High school graduate or less	224 (41.3%)	90 (42.7%)	134 (40.5%)
	Some college or beyond	242 (44.7%)	116 (55.0%)	126 (38.1%)
Household size	Median (Range)	4 (1–5)	3 (1–5)	4 (1–5)
Marital status	Married or living together	165 (30.4%)	54 (25.6%)	111 (33.5%)
	Separate or unmarried	377 (69.6%)	157 (74.4%)	220 (66.5%)
Spirituality/Religiosity	Not very spiritual	316 (58.3%)	136 (64.5%)	180 (54.4%)
	Very spiritual	226 (41.7%)	75 (35.6%)	151 (45.6%)
Difficulty paying monthly bills	Not very or not at all difficult	293 (54.1%)	117 (55.5%)	176 (53.2%)
	Very or somewhat difficult	247 (45.6%)	93 (44.1%)	154 (46.5%)
Site	Midwest region:			
	Cincinnati Children’s Hospital Medical Center	51 (9.4%)	11 (5.2%)	40 (12.1%)
	Lurie Children’s Hospital of Chicago	101 (18.6%)	17 (8.1%)	84 (25.4%)
	Western region:			
	University of California San Francisco Benioff Children’s Hospital Oakland	47 (8.7%)	47 (22.3%)	0 (0.0%)
	Mid-South region:			
	Memphis (St. Jude Children’s Research Hospital)	162 (29.9%)	6 (2.8%)	156 (47.1%)
	Memphis([c]UTHSC)	47 (8.7%)	47 (22.3%)	0 (0.0%)
	Nashville (Vanderbilt University Medical Center)	134 (24.7%)	83 (39.3%)	51 (15.4%)
Patient Health Questionnaire	Mean (SD)	1.08 (1.41)	1.46 (1.55)	0.84 (1.26)
ENRICHD Social Support Instrument (ESSI)	Poor	78 (14.4%)	47 (22.3%)	31 (9.4%)

Variable		**Combined** **(N=542)**	**Adults** **(N=211)**	**Children**[a] **(N=331)**
	Good	464 (85.6%)	164 (77.7%)	300 (90.6%)
Brief Health Literacy Screening	Poor	136 (25.1%)	61 (28.9%)	75 (22.7%)
	Good	406 (74.9%)	150 (71.1%)	256 (77.3%)

[a] Caregivers were asked to report for their children under 18 years, except for Highest degree or level of school completed, marital status, spirituality/religiosity, and difficulty paying monthly bills

[b] Percentages may not add up to 100% because of missing data

[c] UTHSC = University of Tennessee Health Science Center

Table 2.

Item Descriptive Statistics and CFA Factor Loadings, for Provider Communication and Shared DecisionMaking

Domain	CAHPS Item	Mean	SD	N(%)				Factor Loading
				Never	**Sometimes**	**Usually**	**Always**	
Provider Communication	*In the last 12 months, did the sickle cell disease doctor…*							
	explain things in a way that was easy to understand	3.81	0.50	4 (0.7%)	13 (2.4%)	63 (11.6%)	442 (81.6%)	0.919
	listen carefully to you	3.78	0.55	3 (0.6%)	24 (4.4%)	60 (11.1%)	435 (80.3%)	0.94
	show respect for what you had to say	3.84	0.50	5 (0.9%)	13 (2.4%)	45 (8.3%)	459 (84.7%)	0.959
	spend enough time with you (or your child)	3.70	0.60	5 (0.9%)	24 (4.4%)	94 (17.3%)	399 (73.6%)	0.911
Shared Decision Making	*In the last 12 months, did the doctor or other health provider…*			Definitely no	Somewhat no	Somewhat yes	Definitely yes	
	talk with you about the pros and cons of each choice for treatment or health care	3.44	0.94	47 (8.7%)	21 (3.9%)	100 (18.5%)	341 (62.9%)	0.911
	ask which choice you thought was best for you (or your child)	3.44	0.95	48 (8.9%)	24 (4.4%)	92 (17.0%)	346 (63.8%)	0.933

Table 3.

Logistic regression models for hospital admission, readmission, and missed appointment

Hospital Admission				
Combined model (N=508)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**0.54**	**(0.35, 0.83)**	**0.005****
Shared Decision-Making		**1.25**	**(1.00, 1.57)**	**0.054**
Age		1.03	(1.01, 1.05)	0.004**
Sex (Ref = Male)	Female	0.99	(0.68, 1.44)	0.950
African American (Ref = No)	Yes	1.93	(0.34, 10.93)	0.460
Other race (Ref = No)	Yes	0.80	(0.23, 2.82)	0.728
Hispanic (Ref = No)	Yes	1.83	(0.24, 14.07)	0.560
Education (Ref = Some college or more)	High school or less	0.74	(0.48, 1.14)	0.169
	Missing	1.89	(1.02, 3.52)	0.045*
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.80	(0.54, 1.18)	0.251
Marital Status (Ref=Separate or unmarried)	Married or living together	1.33	(0.85, 2.08)	0.207
Household size		0.77	(0.64, 0.92)	0.004**
PHQ score		1.34	(1.15, 1.56)	<0.001**
Spirituality (Ref = Very spiritual)	Not very spiritual	1.13	(0.76, 1.68)	0.557
Social support (Ref=Poor)	Good	0.93	(0.51, 1.70)	0.805
Health literacy (Ref=Poor)	Good	0.97	(0.61, 1.54)	0.898
Adult model (N=175)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**0.57**	**(0.27, 1.21)**	**0.146**
Shared Decision Making		**1.49**	**(0.88, 2.52)**	**0.138**
Age		1.00	(0.96, 1.03)	0.819
Sex (Ref = Male)	Female	0.77	(0.37, 1.61)	0.490
Education (Ref = Some college or more)	High school or less	1.69	(0.81, 3.52)	0.159
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.37	(0.17, 0.81)	0.013*
Marital Status (Ref=Separate or unmarried)	Married or living together	1.87	(0.79, 4.41)	0.154
Household size		0.78	(0.58, 1.04)	0.086
PHQ score		1.34	(1.02, 1.77)	0.037*
Spirituality (Ref = Very spiritual)	Not very spiritual	0.97	(0.45, 2.09)	0.938
Social support (Ref=Poor)	Good	1.16	(0.45, 3.04)	0.758
Health literacy (Ref=Poor)	Good	1.60	(0.70, 3.65)	0.269
Pediatric model (N=330)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**0.54**	**(0.31, 0.94)**	**0.029***
Shared Decision Making		**1.18**	**(0.91, 1.54)**	**0.219**
Age		1.01	(0.96, 1.06)	0.848
Sex (Ref = Male)	Female	0.98	(0.62, 1.56)	0.938
Education (Ref = Some college or more)	High school or less	0.92	(0.53, 1.58)	0.751

	Missing	1.98	(1.02, 3.84)	0.045*
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.99	(0.62, 1.58)	0.959
Marital Status (Ref=Separate or unmarried)	Married or living together	1.26	(0.73, 2.16)	0.412
Household size		0.81	(0.64, 1.03)	0.084
PHQ score		1.29	(1.06, 1.56)	0.010**
Spirituality (Ref = Very spiritual)	Not very spiritual	1.00	(0.62, 1.62)	0.998
Social support (Ref=Poor)	Good	0.90	(0.39, 2.07)	0.802
Health literacy (Ref=Poor)	Good	0.81	(0.45, 1.45)	0.484
Hospital Readmission				
Combined model (N=507)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**0.61**	**(0.36, 1.04)**	**0.070**
Shared Decision Making		**1.38**	**(0.95, 2.00)**	**0.090**
Age		1.04	(1.01, 1.06)	0.002**
Sex (Ref = Male)	Female	1.23	(0.73, 2.08)	0.431
African American (Ref = No)	Yes	1.22	(0.19, 7.91)	0.836
Other race (Ref = No)	Yes	2.02	(0.46, 8.78)	0.351
Hispanic (Ref = No)	Yes	2.14	(0.31, 14.84)	0.442
Education (Ref = Some college or more)	High school or less	0.96	(0.54, 1.69)	0.876
	Missing	1.00	(0.41, 2.47)	0.999
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.57	(0.34, 0.97)	0.038*
Marital Status (Ref=Separate or unmarried)	Married or living together	0.98	(0.54, 1.80)	0.959
Household size		0.95	(0.76, 1.18)	0.628
PHQ score		1.33	(1.12, 1.58)	0.001**
Spirituality (Ref = Very spiritual)	Not very spiritual	0.72	(0.42, 1.23)	0.230
Social support (Ref=Poor)	Good	0.60	(0.30, 1.19)	0.146
Health literacy (Ref=Poor)	Good	1.25	(0.67, 2.33)	0.478
Adult model (N=174)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**1.16**	**(0.47, 2.88)**	**0.743**
Shared Decision Making		**1.13**	**(0.63, 2.03)**	**0.674**
Age		0.98	(0.94, 1.02)	0.266
Sex (Ref = Male)	Female	1.60	(0.72, 3.54)	0.247
Education (Ref = Some college or more)	High school or less	1.00	(0.46, 2.19)	0.999
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.28	(0.13, 0.63)	0.002**
Marital Status (Ref=Separate or unmarried)	Married or living together	1.71	(0.73, 4.01)	0.218
Household size		0.81	(0.60, 1.10)	0.176
PHQ score		1.35	(1.04, 1.75)	0.026*
Spirituality (Ref = Very spiritual)	Not very spiritual	0.35	(0.15, 0.81)	0.013*
Social support (Ref=Poor)	Good	0.59	(0.23, 1.49)	0.263
Health literacy (Ref=Poor)	Good	1.12	(0.46, 2.69)	0.808
Pediatric model (N=330)				
Variable		**OR**	**95% CI**	**p value**

Provider Communication		**0.23**	**(0.09, 0.57)**	**0.002****
Shared Decision Making		**2.38**	**(1.04, 5.43)**	**0.040***
Age		0.98	(0.89, 1.07)	0.626
Sex (Ref = Male)	Female	0.87	(0.38, 1.96)	0.729
Education (Ref = Some college or more)	High school or less	1.12	(0.42, 3.00)	0.817
	Missing	1.58	(0.51, 4.90)	0.429
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	1.32	(0.58, 3.02)	0.514
Marital Status (Ref=Separate or unmarried)	Married or living together	0.64	(0.23, 1.80)	0.401
Household size		1.56	(0.99, 2.47)	0.057
PHQ score		1.38	(1.04, 1.84)	0.027*
Spirituality (Ref = Very spiritual)	Not very spiritual	1.09	(0.46, 2.58)	0.845
Social support (Ref=Poor)	Good	0.88	(0.21, 3.76)	0.867
Health literacy (Ref=Poor)	Good	2.11	(0.69, 6.50)	0.193
Missed Appointment				
Combined model (N=508)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**0.66**	**(0.37, 1.17)**	**0.157**
Shared Decision Making		**1.04**	**(0.81, 1.33)**	**0.772**
Age		1.04	(1.01, 1.06)	0.002**
Sex (Ref = Male)	Female	1.03	(0.65, 1.61)	0.916
African American (Ref = No)	Yes	0.35	(0.04, 2.92)	0.329
Other race (Ref = No)	Yes	0.46	(0.12, 1.81)	0.263
Hispanic (Ref = No)	Yes	0.54	(0.06, 4.55)	0.567
Education (Ref = Some college or more)	High school or less	1.28	(0.77, 2.11)	0.344
	Missing	1.94	(0.90, 4.18)	0.090
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.65	(0.40, 1.03)	0.067
Marital Status (Ref=Separate or unmarried)	Married or living together	0.65	(0.40, 1.08)	0.095
Household size		0.98	(0.79, 1.22)	0.869
PHQ score		0.95	(0.80, 1.13)	0.590
Spirituality (Ref = Very spiritual)	Not very spiritual	1.74	(1.10, 2.77)	0.019*
Social support (Ref=Poor)	Good	0.64	(0.29, 1.42)	0.272
Health literacy (Ref=Poor)	Good	1.27	(0.72, 2.24)	0.405
Adult model (N=175)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**1.86**	**(0.46, 7.59)**	**0.388**
Shared Decision Making		**0.32**	**(0.07, 1.48)**	**0.143**
Age		0.97	(0.92, 1.02)	0.228
Sex (Ref = Male)	Female	0.76	(0.21, 2.78)	0.676
Education (Ref = Some college or more)	High school or less	0.53	(0.14, 2.04)	0.358
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.23	(0.05, 1.11)	0.068
Marital Status (Ref=Separate or unmarried)	Married or living together	1.12	(0.28, 4.54)	0.872
Household size		0.90	(0.54, 1.51)	0.693
PHQ score		0.98	(0.65, 1.49)	0.921

Spirituality (Ref = Very spiritual)	Not very spiritual	1.93	(0.53, 6.99)	0.317
Social support (Ref=Poor)	Good	0.32	(0.03, 3.26)	0.335
Health literacy (Ref=Poor)	Good	4.78	(1.18, 19.41)	0.029*
Pediatric model (N=330)				
Variable		**OR**	**95% CI**	**p value**
Provider Communication		**0.69**	**(0.36, 1.30)**	**0.248**
Shared Decision Making		**1.04**	**(0.80, 1.37)**	**0.760**
Age		0.98	(0.93, 1.04)	0.442
Sex (Ref = Male)	Female	1.15	(0.69, 1.92)	0.585
Education (Ref = Some college or more)	High school or less	1.34	(0.75, 2.38)	0.321
	Missing	1.85	(0.86, 3.99)	0.118
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.66	(0.39, 1.11)	0.115
Marital Status (Ref=Separate or unmarried)	Married or living together	0.57	(0.32, 1.01)	0.052
Household size		1.15	(0.89, 1.48)	0.300
PHQ score		0.87	(0.71, 1.06)	0.167
Spirituality (Ref = Very spiritual)	Not very spiritual	1.38	(0.82, 2.33)	0.227
Social support (Ref=Poor)	Good	1.03	(0.41, 2.59)	0.943
Health literacy (Ref=Poor)	Good	0.91	(0.47, 1.78)	0.778

Note: Pediatric model reflects caregivers’ responses about their children.

Table 4.

Linear regression model for each of the three health literacy items

		Confidence Filling Out Medical Form			Help Reading Health-Related Materials			Problem Learning Medical Condition		
Combined model (N=508)										
Variable		**B**[a]	**95% CI**	**p value**	**B**	**95% CI**	**p value**	**B**	**95% CI**	**p value**
Provider Communication		**−0.01**	**(−0.22, 0.20)**	**0.956**	**−0.18**	**(−0.44, 0.07)**	**0.158**	**−0.28**	**(−0.46, −0.10)**	**0.003****
Shared Decision Making		**0.06**	**(−0.05, 0.18)**	**0.270**	**0.02**	**(−0.11, 0.16)**	**0.734**	**−0.02**	**(−0.12, 0.08)**	**0.685**
Age		−0.01	(−0.02, 0.00)	0.113	0.01	(0.00, 0.02)	0.273	0.01	(0.00, 0.01)	0.114
Sex (Ref = Male)	Female	0.13	(−0.06, 0.33)	0.178	−0.11	(−0.34, 0.13)	0.365	−0.06	(−0.23, 0.11)	0.488
African American (Ref = No)	Yes	0.03	(−0.82, 0.88)	0.949	0.21	(−0.82, 1.23)	0.692	−0.78	(−1.51, −0.05)	0.037*
Other race (Ref = No)	Yes	0.05	(−0.59, 0.70)	0.870	0.71	(−0.07, 1.49)	0.076	0.02	(−0.53, 0.58)	0.935
Hispanic (Ref = No)	Yes	0.12	(−0.80, 1.04)	0.801	0.23	(−0.88, 1.34)	0.681	−0.70	(−1.49, 0.10)	0.085
Education (Ref = Some college or more)	High school or less	−0.49	(−0.70, −0.27)	<.0001***	0.63	(0.37, 0.88)	<.0001***	0.32	(0.13, 0.50)	0.001**
	Missing	−0.75	(−1.07, −0.44)	<.0001***	1.08	(0.70, 1.46)	<.0001***	0.48	(0.21, 0.75)	0.001**
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.15	(−0.05, 0.35)	0.142	−0.02	(−0.26, 0.22)	0.881	−0.03	(−0.21, 0.14)	0.690
Marital Status (Ref=Separate or unmarried)	Married or living together	0.28	(0.05, 0.50)	0.016*	−0.07	(−0.34, 0.20)	0.615	−0.05	(−0.24, 0.14)	0.599
Household size		0.03	(−0.06, 0.12)	0.461	−0.03	(−0.14, 0.07)	0.532	−0.06	(−0.14, 0.01)	0.113
PHQ score		−0.04	(−0.12, 0.03)	0.259	0.06	(−0.03, 0.15)	0.174	0.03	(−0.03, 0.09)	0.350
Spirituality (Ref = Very spiritual)	Not very spiritual	−0.11	(−0.31, 0.09)	0.292	0.16	(−0.09, 0.41)	0.202	0.13	(−0.04, 0.31)	0.139
Social support (Ref=Poor)	Good	0.60	(0.30, 0.90)	<.0001***	0.08	(−0.28, 0.43)	0.675	0.00	(−0.26, 0.25)	0.986
Adult model (N=178)										
Variable		**B**	**95% CI**	**p value**	**B**	**95% CI**	**p value**	**B**	**95% CI**	**p value**
Provider Communication		**−0.13**	**(−0.44, 0.18)**	**0.398**	**−0.02**	**(−0.45, 0.42)**	**0.937**	−0.36	(−0.70, −0.02)	0.037*
Shared Decision Making		**0.16**	**(−0.06, 0.39)**	**0.156**	**−0.23**	**(−0.55, 0.08)**	**0.149**	0.01	(−0.23, 0.25)	0.931
Age		−0.01	(−0.02, 0.01)	0.268	0.00	(−0.02, 0.02)	0.930	0.01	(−0.01, 0.02)	0.351
Sex (Ref = Male)	Female	0.41	(0.10, 0.71)	0.010*	−0.43	(−0.86, 0.01)	0.053	−0.24	(−0.57, 0.09)	0.159
African American (Ref = No)	Yes	−0.20	(−1.27, 0.87)	0.714	0.53	(−0.97, 2.04)	0.484	−0.28	(−1.44, 0.89)	0.640
Other race (Ref = No)	Yes	−0.09	(−0.97, 0.79)	0.838	0.63	(−0.61, 1.87)	0.320	0.39	(−0.57, 1.34)	0.428
Hispanic (Ref = No)	Yes	−0.48	(−1.59, 0.63)	0.397	0.86	(−0.70, 2.42)	0.276	0.12	(−1.08, 1.32)	0.842
Education (Ref = Some college or more)	High school or less	−0.36	(−0.66, −0.05)	0.022*	0.24	(−0.19, 0.66)	0.278	0.22	(−0.11, 0.55)	0.191

		Confidence Filling Out Medical Form			Help Reading Health-Related Materials			Problem Learning Medical Condition		
	Missing	−0.71	(−1.92, 0.51)	0.252	1.46	(−0.25, 3.17)	0.093	0.77	(−0.55, 2.09)	0.253
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	0.72	(0.41, 1.03)	<.0001***	−0.13	(−0.57, 0.30)	0.551	−0.46	(−0.80, −0.12)	0.008**
Marital Status (Ref=Separate or unmarried)	Married or living together	0.34	(0.00, 0.68)	0.052	−0.17	(−0.65, 0.31)	0.496	−0.03	(−0.40, 0.34)	0.875
Household size		−0.04	(−0.16, 0.08)	0.493	0.05	(−0.12, 0.22)	0.553	−0.02	(−0.15, 0.11)	0.742
PHQ score		0.05	(−0.06, 0.15)	0.360	−0.02	(−0.17, 0.12)	0.747	−0.01	(−0.13, 0.10)	0.811
Spirituality (Ref = Very spiritual)	Not very spiritual	−0.11	(−0.44, 0.21)	0.493	0.13	(−0.33, 0.59)	0.581	0.04	(−0.31, 0.39)	0.822
Social support (Ref=Poor)	Good	0.12	(−0.26, 0.51)	0.527	0.14	(−0.40, 0.68)	0.611	0.09	(−0.33, 0.50)	0.688
Pediatric model (N=330)										
Variable		**B**	**95% CI**	**p value**	**B**	**95% CI**	**p value**	**B**	**95% CI**	**p value**
Provider Communication		**0.07**	**(−0.22, 0.37)**	**0.625**	**−0.18**	**(−0.52, 0.16)**	**0.296**	−0.20	(−0.43, 0.03)	0.084
Shared Decision Making		**0.01**	**(−0.13, 0.15)**	**0.869**	**0.08**	**(−0.08, 0.24)**	**0.346**	−0.03	(−0.13, 0.08)	0.641
Age		−0.02	(−0.04, 0.01)	0.276	0.00	(−0.03, 0.04)	0.820	0.00	(−0.02, 0.02)	0.841
Sex (Ref = Male)	Female	0.08	(−0.17, 0.33)	0.542	0.02	(−0.27, 0.31)	0.912	−0.03	(−0.22, 0.17)	0.788
African American (Ref = No)	Yes	0.20	(−1.15, 1.54)	0.775	−0.09	(−1.63, 1.45)	0.906	−1.43	(−2.46, −0.39)	0.007**
Other race (Ref = No)	Yes	0.35	(−0.56, 1.26)	0.453	0.79	(−0.26, 1.84)	0.140	−0.35	(−1.05, 0.36)	0.333
Hispanic (Ref = No)	Yes	0.53	(−0.96, 2.02)	0.486	−0.60	(−2.32, 1.11)	0.488	−1.61	(−2.76, −0.46)	0.006**
Education (Ref = Some college or more)	High school or less	−0.50	(−0.79, −0.21)	0.001**	0.85	(0.52, 1.18)	<.0001***	0.35	(0.13, 0.58)	0.002**
	Missing	−0.81	(−1.18, −0.45)	<.0001***	1.22	(0.80, 1.64)	<.0001***	0.47	(0.18, 0.75)	0.001**
Difficulty paying monthly bills (Ref = Very or somewhat difficult)	Not very or not at all difficult	−0.07	(−0.33, 0.19)	0.593	−0.03	(−0.33, 0.26)	0.824	0.18	(−0.02, 0.37)	0.083
Marital Status (Ref=Separate or unmarried)	Married or living together	0.23	(−0.06, 0.52)	0.125	0.01	(−0.33, 0.35)	0.945	−0.09	(−0.32, 0.13)	0.425
Household size		0.09	(−0.04, 0.22)	0.174	−0.07	(−0.22, 0.07)	0.321	−0.09	(−0.19, 0.01)	0.064
PHQ score		−0.08	(−0.18, 0.03)	0.150	0.06	(−0.06, 0.17)	0.353	0.04	(−0.04, 0.12)	0.319
Spirituality (Ref = Very spiritual)	Not very spiritual	−0.11	(−0.38, 0.15)	0.394	0.13	(−0.18, 0.43)	0.417	0.17	(−0.04, 0.37)	0.107
Social support (Ref=Poor)	Good	1.04	(0.59, 1.48)	<.0001***	−0.01	(−0.52, 0.50)	0.981	0.06	(−0.28, 0.40)	0.738

[a] B = regression coefficient