Health-Related Communication in Adolescents and Young Adults with Sickle Cell Disease

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Abstract

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Background and Aims: Effective health-related communication is essential for pain and disease management but is poorly understood among adolescents and young adults (AYAs) with sickle cell disease (SCD). The current study aimed to: (1) Characterize the quality and prevalence of communication difficulties among AYAs with SCD; (2) Identify sociodemographic/disease-related factors associated with communication difficulties; and (3) Examine associations between pain, pain interference, and communication difficulties.

Method: AYAs with SCD (N=416; mean [*M*] age=18.6 years, range=13.2-25.0, 50% female, 99.8% Black; n=136 adolescents; n=280 young adults) enrolled in the Sickle Cell Clinical Research and Intervention Program completed the PedsQL-SCD, which contains subscales measuring self-advocacy (Communication I), eliciting understanding (Communication II), pain (Pain and Hurt), and pain interference (Pain Impact). Clinical data were extracted from medical records. Analyses included descriptive statistics, multivariate regressions (adjusted for age, sex, and genotype), with false discovery rate corrections.

Results: AYAs reported moderate-to-good quality communication (*M*=20.6 for self-advocacy; *M*=37.2 for eliciting understanding). However, 26.4% of AYAs reported feeling misunderstood about their pain and 22.3% reported feeling misunderstood about their disease. Female sex, greater economic hardship, older age, and Hb SS/Sβ^0 genotype were associated with greater communication difficulties (all ps<0.05). Elevated pain and pain interference were also associated with communication difficulties ($p<0.001$).

Conclusion: These findings improve our understanding of health-related communication among AYAs with SCD and highlight factors associated with communication difficulties. Tailored interventions are needed to improve care and health outcomes among this population.

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Introduction

Sickle cell disease (SCD) is a chronic hereditary blood disorder affecting 7 million people worldwide (Piel et al., 2017). It is characterized by a genetic mutation that causes sickle-shaped red blood cells, which have a reduced ability to flow and deliver oxygen (National Heart, Lung, and Blood Institute [NHLBI], 2023). The genetic trait for SCD helps protect against malaria and is prevalent in regions where malaria is or was common (Williams et al., 2005). Thus, most people who have SCD are of African descent or identify as Black (NHLBI, 2023). In the United States, SCD affects approximately 100,000 people. In Canada, over 6,000 people live with SCD (Sickle Cell Awareness Group of Ontario, 2021; Sickle Cell Disease Collaborators, 2023).

Serious complications like stroke and organ damage are common in SCD and can begin in infancy (NHLBI, 2023; Piel et al., 2017). The hallmark SCD symptom is acute, recurrent pain episodes (vaso-occlusive crises), which vary in frequency and intensity and often require hospitalization (Brousseau et al., 2010). Around 30-40% of individuals with SCD also experience chronic pain (Sil et al., 2016; 2020; Smith et al., 2008), defined as pain which persists for at least 6 months (Dampier et al., 2017). Vaso-occlusive pain crises and chronic pain can severely disrupt daily life and limit participation in work and school (Poku et al., 2018; Thomas et al., 2002). Individuals with SCD face challenges with social support, daily activities, maintaining education or employment, and are at increased risk of anxiety and depression, insomnia, fatigue, and neurocognitive impairments (Holdford et al., 2021; Osunkwo et al., 2021; Thomas & Taylor, 2002). While treatments like hydroxyurea and bone marrow transplants have improved health outcomes (NHLBI, 2023), racial disparities in healthcare have been documented for decades and have been shown to worsen both the burden of SCD and the undertreatment of SCD-related pain across the lifespan (Hoffman et al., 2016; Reich et al., 2023; L. Smith et al., 2006).

Health-Related Communication and SCD

This increased disease burden and undertreatment of pain may be partially due to communication-related barriers such as lack of provider knowledge, mistrust, stigma, and discrimination (Bulgin et al., 2018; Crosby et al., 2009; Mulchan et al., 2024; Renedo et al., 2019; Wright & Adeosun, 2009) – many of which are rooted in the racialized nature of SCD (Reich et al., 2023; Ruta & Ballas, 2016). Indeed, in comparison to White patients, Black patients with SCD and other diseases receive less information from their providers and describe more reluctance to share questions, concerns, and treatment preferences (Haywood et al., 2014; Saha et al., 2008).

Communication in SCD involves patients conveying information about their disease, including explaining what it is, describing their symptoms (e.g., pain), or asking for help. This information is received and interpreted by others in their lives, such as providers, parents, siblings, teachers, employers, and peers.

Consistent with current theoretical models of pain and disease communication, communication within the current study is viewed as a *social transaction* influenced by a complex system of biological, psychological, social, and contextual factors that likely amplify health disparities in SCD (Drossman et al., 2021; Hadjistavropoulos et al., 2011; Kahana & Kahana, 2003; Shiavenato & Craig, 2010). Here broader sociocultural and structural factors such as stigma, racialization, mistrust, and socioeconomic status can also influence these interactions (Reich et al., 2023; Renedo et al., 2019). More specifically, within biopsychosocial models of pain communication, the individual experiencing pain brings to the encounter not only their current pain experience, but also their emotional state, past experiences, and beliefs about pain – all of which can influence how they express discomfort. Conversely, the listener or receiver of this information, whether a clinician, family member, or peer, interprets and responds to pain expression through the lens of their own expectations, knowledge, and relational context. This dynamic exchange can determine immediate care decisions and have enduring effects on health behaviours (Hadjistavropoulos et al., 2011; Shiavenato & Craig, 2010). For example, youth and adults with SCD who face negative emergency room encounters during pain crises report avoiding future professional care, electing to endure severe pain at home rather than risk repeat adverse care seeking experiences (Jenerette et al., 2014; Kanter et al., 2020). Kahana and Kahana's Healthcare Partnership Model (2003) extends the biopsychosocial view into clinical care and communication with significant others in patients' lives (e.g., family, caregivers) in addition to healthcare providers, emphasizing both the content (i.e., what is communicated) and relational aspects (i.e., how it is communicated) of communication patterns. Relevant relational aspects of health communication encounters in SCD may include shared decision-making, respectfulness, supportiveness, and patient assertiveness (Collins et al., 2022). Effective health partnership fosters open dialogue about treatment adherence, lifestyle modifications, and psychosocial coping strategies that help ensure optimal support and care for patients with SCD. Theoretical models show that successful pain and disease management in SCD depends on a continuous, bidirectional flow of information: patients must feel safe and equipped to articulate both somatic and psychosocial challenges, and their support network must be trained to listen actively, respond empathetically, and collaborate on practical solutions (Hadjistavropoulos et al., 2011; Kahana & Kahana, 2003; Shiavenato & Craig, 2010).

In the chronic disease and SCD literature, it is well established that good communication with both healthcare providers and others (e.g., parents, friends) is associated with positive behavioural and social outcomes including better medical adherence and self-management skills, positive social relationships, and reduced healthcare utilization (Derlega et al., 2014; Drossman et al., 2021; Haywood et al. 2014; Cronin et al., 2020; Ha & Longnecker, 2010; Porter et al., 2017). In contrast, poor communication has been associated with negative outcomes including poor pain and disease management, higher cost of care, and lower quality of life (Cronin et al., 2020; Crosby et al., 2009; Drossman et al., 2021; Ha & Longnecker, 2010; Haywood et al., 2014). Regarding potential risk and protective factors around poor communication, findings from the broader chronic disease literature have been mixed. For example, among individuals diagnosed with lupus, greater disease severity has been associated with increased communication difficulties (Sun et al., 2021), while no clear association between disease severity and communication difficulties has been found among individuals with Type 2 diabetes (White et al., 2016). With respect to SCD, older age, lower income, and greater disease severity have been linked to poorer patient-provider communication among adults (Haywood et al., 2010; 2014). However, few studies have examined potential associations between communication and sociodemographic and disease-related factors among individuals with SCD and no studies have examined these outcomes among adolescents and young adults with SCD specifically.

Adolescents and Young Adults with SCD

Adolescents (13-17 years) and young adults (18-25 years) (AYAs; Bonnie et al., 2015; Ross et al., 2020) with SCD face a unique set of communication barriers (Porter et al., 2017). In addition to developmental changes like gaining independence from parents and adjusting to new roles in education, work, and social domains (Porter et al., 2017; Baskin et al., 1998), AYAs must also transition from pediatric to adult care – a period marked by increased pain, emergency care use, and mortality (Alberts et al., 2021; Howell et al., 2023; Blinder et al., 2013, 2014; Quinn et al., 2010). Adding to the challenges and complexity of transition, AYAs must also adapt to taking on more responsibility for managing their disease as they move to adult care. Health-related communication between patients, and both healthcare providers and others (e.g., parents, peers) therefore plays an increasingly important role in disease and pain management as AYAs navigate the transition from pediatric to adult care. Yet, AYAs with SCD report substantial difficulties in communicating with adult care providers (Collins et al., 2022; Crosby et al., 2009; Jenerette et al., 2014; Kanter et al., 2020; Poku et al., 2018; Porter et al., 2017; Renedo et al., 2019) and others in their lives (Barakat et al., 2008; Bemrich-Stolz et al., 2015; Collins et al., 2020; Derlega et al., 2014; Graff et al., 2012; Jenerette et al., 2014).

Despite the importance of effective health-related communication and the presence of communication barriers among AYAs with SCD, only one study to our knowledge has examined health-related communication as a primary variable among patients with SCD (Varni & Panepinto, 2020). However, this study investigated health-related communication as a mediator of the effects of pain in youth ages 5 to 18 years and contained a limited examination of biopsychosocial factors potentially associated with health-related communication difficulties (Varni & Panepinto, 2020). In addition, no studies to our knowledge, have characterized health-related communication difficulties among AYAs with SCD specifically. Improved characterization and understanding of health-related communication difficulties in this population could help inform tailored interventions to improve communication and, in turn, pain management and health outcomes in AYAs with SCD.

The current study therefore aimed to: 1) Characterize the overall communication quality and prevalence of health-related communication difficulties among AYAs with SCD; (2) Identify sociodemographic/disease-related factors associated with health-related communication difficulties; and (3) Examine associations between pain, pain interference, and health-related communication difficulties. For Aim 1, it was hypothesized that increased health-related communication difficulties would be observed for AYAs (i.e., elevated Communication I and II Subscales scores on the PedsQL-SCD Module, as well as individual item scores). In addition, it was hypothesized that young adults would report more difficulties with health-related communication compared to adolescents. For Aim 2, it was hypothesized that older age, greater economic hardship, and higher disease severity would be associated with more health-related communication difficulties for AYAs with SCD. For Aim 3, it was hypothesized that elevated pain and pain interference would be associated with greater health-related communication difficulties among AYAs with SCD.

Methods

Participants

The sample consisted of 416 AYAs, which included 280 adolescents (aged 13-17 years) and 136 young adults (aged 18-25 years) with SCD. All participants were enrolled in the Sickle Cell Research and Intervention Program (SCCRIP; NCT02098863), which is based at St. Jude Children's Research Hospital in Memphis, Tennessee and enrolls patients with SCD who are treated at St. Jude and additional hospitals across the Southeast and Midwest United States. SCCRIP is a longitudinal cohort study designed to investigate the progression of SCD within clinical, biological, and psychosocial domains and across the lifespan (Hankins et al., 2018). Inclusion criteria in the current study were: 1) 13 to 25 years of age, 2) diagnosed with SCD, 3) received treatment at one of five participating SCCRIP sites, and 4) completed the teen or young adult version of the PedsQL-SCD. The SCCRIP protocol was approved by all institutional review boards, and informed consent and assent was obtained from participants (or legal guardians for minors) before collection of study data. The current study also received Concordia University Human Research Ethics Committee approval for secondary data analysis in November 2023 (Certification Number: 30019195).

Procedure

Recruitment and data collection took place at routine hematology clinic visits. Participants completed self-report measures on a tablet device. Automated and manual data abstraction was used to collect demographic, disease and treatment-related data from medical charts. Measures collected at the first PedsQL-SCD assessment point between 2014 and 2018 were used in the current study. For a detailed description of SCCRIP and its data collection processes, see Hankins et al. (2018).

Measures

Disease-related, clinical, and sociodemographic variables. Laboratory data obtained on the same day or the day closest to self-report measure completion were used. Disease and clinical variables extracted from the SCCRIP database included: SCD genotype, history of silent and overt stroke, whether participants were currently receiving hydroxyurea therapy, and whether participants were currently receiving chronic blood transfusions. The Economic Hardship Index (EHI; Nathan & Adams, 1976) was used to assess neighborhood-level socioeconomic characteristics. Here, participants are aggregated to the Census Block Group level using geographic information systems, specifically ArcGIS (2020), by geocoding home address. The EHI value is the mean of six variables (unemployment, education, income, poverty level, housing units with >1 person per room, and age dependency) obtained from the US Census American Community Survey and standardized on a scale of 0 to 100. Higher values indicate more neighborhood hardship.

Health-related communication. The Communication I and Communication II Subscales of the Pediatric Quality of Life Inventory-Sickle Cell Disease Module (PedsQL-SCD; Panepinto et al., 2011) were used to measure health-related communication. Both the adolescent and young adult versions of the PedsQL-SCD were used in the current study. Items are rated on a 5-point Likert scale assessing the frequency of problems with communication over the past month (i.e., 0=*never* to 4=*almost always*). The Communication I Subscale consists of three items measuring problems in self-advocacy-related communication. Specifically, communicating to others when in pain and sharing questions and feelings with healthcare providers (Panepinto et al., 2011). The Communication II Subscale consists of three items measuring problems related to eliciting understanding from others. Specifically, when disclosing the patient's SCD diagnosis (self-disclosure), and their pain and disease being misunderstood (Panepinto et al., 2011). The authors of the PedsQL-SCD have not characterized Communication Subscales I or II beyond the descriptions provided in the initial factor analysis study (Panepinto et al., 2011), but previous work using this measure has described the communication subscales in a manner consistent with the current study (Barten-Gooden et al., 2019; Hardy et al., 2018). For the current analyses, items were linearly transformed to a 0 to 100 scale (i.e., 0=0, 1=25, 2=50, 3=75, and 4=100), such that higher scores indicated greater communication difficulties. Both Communication Subscales I and II demonstrated acceptable to good internal consistency across all groups (α= 0.73-0.82).

Pain and pain interference. The Pain and Hurt as well as the Pain Impact subscales of the PedsQL-SCD module were used to measure pain and pain interference, respectively. The Pain and Hurt Subscale consists of nine items measuring pain intensity, frequency, and location. The Pain Impact Subscale consists of ten items measuring the degree to which pain interferes with activities such as daily living, socializing, and work/school. Items are rated on a 5-point Likert scale assessing the frequency of problems with communication over the past month (i.e., 0=*never* to 4=*almost always*). For the current analyses, items were linearly transformed to a 0 to 100 scale (i.e., 0=0, 1=25, 2=50, 3=75, and 4=100), such that higher scores indicated greater pain and pain interference. Both the Pain and Hurt and the Pain Impact Subscales demonstrated acceptable to good internal consistency across all groups (α= 0.91-0.93).

Statistical Analysis

All analyses were conducted for the overall sample of AYAs (N=416) and for each age group: adolescents (n=280) and young adults (n=136). Descriptive statistics were calculated for the sample characteristics, including age, sex, race, genotype, EHI, and disease and treatment-related factors.

For Aim 1, we calculated descriptive statistics for mean overall scores from the PedsQL-SCD Communication I Subscale and Communication II Subscale as well as mean scores for each individual subscale item. Mean scores for the Communication I Subscale and Communication II Subscale were used to assess the quality of health-related communication. The percentage of participants whose mean scores on the Communication I Subscale and on the Communication II Subscale were ≥75, as well as those with individual item scores of ≥75 (indicating problems occurred *often* or *almost always* in the past month), was calculated to assess prevalence of communication difficulties (Haywood et al., 2014). The Chi-square test was used to compare the prevalence of communication difficulties across the two age groups. The Wilcoxon rank sum test was used to compare mean communication subscale scores between the two age groups. Regarding significance testing, $p<0.05$ was considered statistically significant for the primary outcome of health-related communication.

For Aims 2 and 3, we constructed multiple linear regression models to examine associations between health-related communication and: 1) demographic and disease-related variables and 2) pain-related variables. Univariate and multivariable linear regression models were used to estimate mean effects (β) with standard errors of the relationship between potential risk factors and scores on health-related communication. Prior to developing multivariable models, we examined the association between communication and demographic variables (i.e., age, sex, genotype) to inform adjustments for subsequent multivariable models. Separate models were developed for the Communication I Subscale and the Communication II Subscale. Variables with high Variance Inflation Factor were excluded to minimize multicollinearity. Variables included in the final multiple linear models were first selected based on a combination of prior literature and univariate analyses ($p<0.05$). A stepwise selection approach with both forward and backward selection was then applied. The Akaike Information Criterion was used to determine the most parsimonious model fit (Kline, 2016).

A power analysis was conducted using G*Power version 3.1 software (Faul et al., 2009). The current sample sizes of 136 adolescents, 280 young adults, and in total 416 participants give 90% statistical power to detect small to medium effect sizes of ≥0.10 and ≥0.30, respectively, at a significance level of 0.025 (=0.05/2) based on a two-sided test (Panepinto et al., 2013). The false discovery rate adjusted *p*-values or *q*-values were calculated to correct for multiple comparisons. R Version 4.4.0 (R Core Team, 2024) was used for analysis.

Results

Data Screening

Prior to analysis, the dataset was screened for completeness and quality. Among the 416 participants, most variables had no missing values. A small number of variables including EHI had limited missingness (maximum of 11 (3%) cases each). Missing data for both communication subscale scores were also minimal at less than 1.5% on each. Additionally, individual items within communication subscales had only 3-4 missing values (<1%) each, indicating negligible levels of missingness unlikely to bias results (Kline, 2013). Outliers were evaluated using the interquartile range and Z-score methods (Kline, 2013) and the proportion of outliers was very low across all continuous variables. Outliers were included in the current analysis as these responses may represent true correct values (Kline, 2013). In the overall group, items within Communication Subscale I were moderately correlated (e.g., r= 0.59), and strong correlations were observed among items in Communication Subscale II (e.g., r= 0.75). This is in line with previous factor analysis (α= 0.70 for both subscales) (Panepinto et al., 2013).

Sample Characteristics

Sample demographics and clinical characteristics Crof AYAs who participated in the current study are shown in Table 1. Participants were on average 18.6 years old (*SD*=2.6; range=13.2-25.0). Half of AYAs were female (50%), almost all identified as Black (99.8%), and 65% had Hb SS/Sβ0 – thalassemia genotype. Almost half of the AYAs (48%) were receiving hydroxyurea at the time of the study and 12.3% were receiving chronic transfusions. Most participants had moderate to high levels of economic hardship, with 73.8% of participants having an EHI score that was moderate or greater.

Quality and Prevalence of Health-Related Communication Difficulties

Table 2 shows the quality (mean subscale score) and prevalence (%) of communication difficulties (score ≥75) for the Communication I Subscale and Communication II Subscale by age group and the overall sample. The mean overall communication scores among AYAs with SCD were 20.6 (*SD*=22.8) for difficulties with self-advocacy (i.e., Communication I Subscale), and 37.2 (*SD*=28.8) for eliciting understanding (i.e., Communication II Subscale), indicating moderate to good quality communication. Difficulties with self-advocacy were comparable for adolescents (*M*=19.9, *SD*=23.1) and young adults (*M*=22.1, *SD*=22.3, *p*=0.29). Difficulties with eliciting understanding were greater for young adults (*M*=40.7, *SD*=26.3) compared to adolescents (*M*=35.5, *SD*=29.9, *p*=0.03). Overall, 2.9% of AYAs (n=12) had a mean score that indicated difficulties with self-advocacy occurred, on average, *often* or *almost always* in the past month (score ≥75 on the item) and 12.4% of AYAs (n=51) had a mean score that indicated difficulties eliciting understanding occurred, on average, *often* or *almost always* in the past month.

Figure 1 shows the prevalence (%) of specific communication difficulties (score ≥75 on each individual item). Among the overall sample, the most common communication difficulty reported was "*It is hard for me when others do not understand how much pain I feel*," with 26.4% of AYAs reporting this occurred *often* or *almost always* in the past month. A greater number of young adults than adolescents reported *often* or *almost always* on this item (33.3% vs. 23.0%, *p*=0.03). The second most common communication difficulty was "*It is hard for me when others do not understand about my sickle cell disease*," which was endorsed by 22.3% of AYAs, followed by "*It is hard for me to tell others I have sickle cell disease*," which was endorsed by 19.4% of AYAs. No differences were observed between adolescents and young adults on these items (*ps*= 0.17 and 0.08). For the overall sample, the least endorsed items included: "*It is hard for me to tell the doctors and nurses how I feel"* (6.8%) and "*It is hard for me to ask the doctors and nurses questions"* (5.3%). No differences between were observed between age groups on these items (*ps*= 1.0 and 0.74).

Sociodemographic and Disease-Related Factors and Health-Related Communication Difficulties

Tables 3a and 3b show linear regression analysis results of health-related communication and sociodemographic, treatment, and disease-related variables for adolescents, young adults, and the overall sample of AYAs, adjusted for age, sex, and genotype. Results of the univariate analyses are contained in the Appendix (Supplemental Table 1 and Supplemental Table 2). *Q*-values are only reported if statistically significant (q<.05). A *q*-value is the false discovery rate; it is an adjusted *p*-value to control for multiple comparisons.

In the univariate models, female sex was associated with greater self-advocacy communication difficulties for adolescents (β= 6.8, *p*= 0.014), young adults (β= 9.90, *p*= 0.009), and the overall sample (β= 7.80, *p*= 0.0005, *q*= 0.004). Female sex was also associated with greater difficulties eliciting understanding for adolescents (β= 8.10, *p*= 0.024), young adults (β= 16, *p*= 0.0003, *q*= 0.007), and the overall sample (β= 11, *p*= 0.0002, *q*= 0.003). Age and genotype Hb SS/Sβ0 were not associated with self-advocacy communication difficulties for any group. Older age was associated with greater difficulties with eliciting understanding for the overall sample only (β= 1.1, *p*= 0.05). Genotype Hb SS/Sβ0 (i.e., more severe disease) was associated with greater difficulties with eliciting understanding for adolescents (β= 7.80, *p*= 0.037, *q*= 0.03) and the overall sample (β= 7.80, *p*= 0.0005, *q*= 0.04). Multivariate sociodemographic and disease-related models were therefore adjusted for age, sex and genotype.

In multivariable models adjusted for age, sex, and genotype, compared to AYAs with very low economic hardship, moderate and high economic hardship was associated with greater self-advocacy difficulties for adolescents (βs= 13 and 12, *p*s= 0.027 and 0.050). Very high and high economic hardship was associated with greater difficulties with eliciting understanding for adolescents (βs= 20.00 and 17.00, *p*s= 0.04 and 0.03) and the overall sample (βs= 17.00 and 13.00, *p*s= 0.03 and 0.04), as compared to very low economic hardship. Current use of hydroxyurea, current chronic transfusions, and history of stroke were not significantly associated with either communication outcome (*ps*= 0.21-0.83).

Pain and Health-Related Communication Difficulties

Table 4 shows associations between health-related communication and pain outcomes, adjusted for age, sex, and genotype. Q-values are only reported if statistically significant (q<.05).

Elevated pain was associated with greater difficulties with self-advocacy for adolescents (β= 0.47, *p*= 4.70E-15), young adults (β= 0.43, *p*= 1.60E-07), and the overall sample (β= 0.45, *p*= 5.40E-21). Elevated pain was also associated with greater difficulties eliciting understanding for adolescents (β= 0.48, *p*= 2.20E-09), young adults (β= 0.38, *p*= 6.30E-05), and the overall sample (β= 0.44, *p*= 6.60-13). With respect to pain interference, elevated pain interference was associated with greater difficulties with self-advocacy for adolescents (β= 0.44, *p*= 6.27-15), young adults (β=

0.38, *p*= 3.60E-06), and the overall sample (β= 0.41, *p*= 1.29E-19). Elevated pain interference was also associated with greater difficulties eliciting understanding for adolescents (β= 0.57, *p*= 2.20E-15), young adults (β= 0.45, *p*= 2.10E-06), and the overall sample (β= 0.53, *p*= 1.20E-20).

Discussion

Health-related communication is an important component of disease and pain management for AYAs with SCD. Pain in SCD is extensive and impacts the overall wellbeing of patients and their caregivers (Alberts et al., 2021; Howell et al., 2023; Sil et al., 2020; Smith et al., 2008). Increasing reports of communication-related barriers to SCD pain management (Collins et al., 2022; Liederman et al., 2020; Mulchan et al., 2016; Haywood et al., 2014; Wright & Adeoson, 2009) and high disease burden for AYAs call for a better understanding of health-related communication and contributing factors among AYAs with SCD. The current study sought to examine health-related communication in a large sample of AYAs with SCD who participated in SCCRIP, a prospective clinical cohort study. To our knowledge, this is the first study to characterize health-related communication difficulties and examine demographic, disease, and pain-related factors associated with communication difficulties across adolescence and young adulthood in SCD.

Consistent with our hypothesis, a notable subset (12.4%) of AYAs with SCD reported difficulties with eliciting understanding from others as having occurred *often* or *almost always*, on average, in the past month. Mean total scores in this area (Communication II Subscale) for adolescents and young adults each also indicated elevated communication difficulties. These findings are consistent with a prior study of health-related quality of life among adolescents with SCD in Jamaica, where results also showed difficulties related to eliciting understanding from others as indicated by the Communication II Subscale of the PedsQL-SCD (Barten-Gooden et al., 2019). With respect to specific communication difficulties, just over one quarter of AYAs in the current study reported problems with others not understanding their pain, 22% reported problems with others not understanding their disease, and 19% reported difficulties disclosing their SCD to others. Our findings pertaining to difficulties with pain communication specifically are consistent with literature showing that AYAs with SCD often contend with unhelpful responses to their pain by others, including family members and friends (e.g., others responding in an inconvenienced, fearful, upset manner), and emergency providers (e.g., undertreated, labelled as drug-seeking) (Collins et al., 2020; Liederman et al., 2020). Within the school context, adolescents have reported that the onset of sickle cell pain at school led to hostility and emotional upset among peers and teachers, and that teachers were not always accommodating of their SCD selfcare needs (e.g., not allowing a coat to be worn in class) (Dyson et al., 2011). Young adults and adults with SCD have also reported that when they are experiencing significant and uncontrolled pain, it is difficult for them to communicate this pain to and constructively engage with providers (Liederman et al., 2020) – which likely impacts providers' ability to fully understand the patient's pain. Reduced communication with providers in this context likely further contributes to the undertreatment of pain and to further difficulties with communicating and receiving the pain message – leading to a vicious cycle. These difficulties highlight the complex and interactional nature of pain and disease communication among AYAs with SCD.

Age differences in health-related communication were also observed. As hypothesized, young adults experienced more communication difficulties than adolescents with respect to specific communication difficulties (e.g., having their pain or disease misunderstood) and within the domains of self-disclosure and eliciting understanding. Although differences between age groups in the quality of communication (mean scores) and prevalence of communication difficulties related to self-advocacy were not observed, differences in eliciting understanding were identified. Young adults were more likely than adolescents to report problems with others misunderstanding their pain, while there was no difference between age groups in problems with disclosing their diagnosis. These findings may be due to developmental differences and differences in disease trajectory. For example, young adults have likely had more practice in self-disclosure skills than adolescents, which may reduce communication problems in that area. Conversely, compared to adolescents, young adults must manage increasing disease and pain burden, and a relatively new adult care environment – all with likely reduced support from parents and increasing expectations to manage these burdens more independently (Porter et al., 2017). This in turn may lead to more negative experiences being misunderstood, for example, when seeking emergency care for a pain crisis (Collins et al., 2020; Kanter et al., 2020; Porter et al., 2017). Our finding of more difficulties with eliciting understanding specifically for young adults compared to adolescents also aligns with reports of young adults with SCD frequently having to manage unhelpful responses to their pain, for example, from concerned family or unsympathetic employers (Barakat et al., 2008; Bemrich-Stolz et al., 2015; Collins et al., 2020; Derlega et al., 2014; Graff et al., 2012; Jenerette et al., 2014). Thus, it is possible that age-related differences in communication for AYAs with SCD exist not only in self-advocacy skills, but in how pain is interpreted and responded to by others – reflecting the bidirectional nature of health-related communication.

We found strong associations between female sex and communication difficulties. This finding could reflect sex and gender disparities in pain and pain management that have been observed in the general population (Bimpong et al., 2022; Koegh et al., 2025; Pieretti et al., 2019; Mazzocca et al., 2025). For Black women and girls with SCD, it is possible that intersecting gender and race biases exacerbate these disparities, hindering communication and worsening pain outcomes (Hoffman et al., 2016; Yearby, 2018). In a study examining sex differences on outcomes within the PedsQL-SCD measure, adolescent girls with SCD reported significantly more problems eliciting understanding (i.e., Communication II Subscale) about their pain and disease than boys (Barten-Gooden et al., 2019). Our findings are also consistent with literature showing evidence of increased difficulties with pain communication among parents and daughters compared to parents and their sons. Specifically, pediatric pain populations, including youth with SCD (Alberts et al., 2024), have demonstrated higher agreement on pain ratings between caregivers and sons compared to daughters (Blake et al., 2020; Cohen et al., 2010; Schwartz et al., 2013). Taken together, these findings suggest that compared to their male counterparts, female AYAs with SCD may be more at risk of having pain communication difficulties with their caregivers, providers, or others in their lives. However, further research is needed to explore these complex interactions more thoroughly.

As hypothesized, we observed an association between the Hb SS/Sβ0 genotype and difficulties eliciting understanding. These findings are consistent with recent evidence and theoretical models of pain and disease communication which indicate that an increase in the number and severity of health complications related to the disease can diminish overall functioning and can interfere with effective communication (Hadjistavropoulos et al., 2011; Liederman et al., 2020). Notably, reduced neurocognitive functioning (i.e., problems with executive function, comprehension, attention) is well documented among youth and adults with SCD (Sahu et al., 2022), and could significantly impact AYAs' abilities to communicate with others and engage with adult care (Ali et al., 2020; Connolly et al., 2019; Longoria et al., 2022; Sahu et al., 2022; Varni & Panepinto, 2020). For example, difficulties with attention and working memory are common among youth with SCD (Hijmans et al., 2011), and could hinder AYAs' expressive or receptive communication, leading to misunderstandings about their pain and disease. The lack of association found between communication difficulties and Hb SS/Sβ0 genotype among young adults in the current study, could signal experience-based gains in communication skills despite disease severity. More research is needed to understand the impact of disease severity on communication.

In the current study, higher economic hardship was associated with more difficulties with eliciting understanding and self-advocacy for adolescents and the overall sample. Developmental and socioeconomic influences may explain these findings (Hadjistavropoulos et al., 2011; Kahana & Kahana, 2003). More specifically, socioeconomic stressors like housing and food insecurity can deplete AYAs' mental resources for health-related communication, which may contribute to difficulties with self-advocacy and eliciting understanding (Khan et al., 2023; Porter et al., 2023; Schiavenato & Craig, 2010). For example, factors such as health literacy or capacity (e.g., time, resources) for self-advocacy may be reduced among AYAs with SCD of lower socioeconomic status and their caregivers compared to those with more education or resources (Porter et al., 2023). However, provider factors, including potential biases, and the role they play in health-related communication should also be considered (Liederman et al., 2020). Racial bias from providers is another longstanding issue in SCD (Reich et al., 2023), which can contribute to AYAs and their caregivers taking a more cautious communication approach, for example, to avoid being viewed negatively and as drug-seeking (Collins et al., 2020; Reich et al., 2023; Renedo et al., 2019). More research is needed to assess socioeconomic correlates of communication in AYAs with SCD, and the complex communication interactions that occur between AYAs and their healthcare providers.

As expected, elevated pain and pain interference were strongly associated with more communication difficulties. These findings closely align with the extant SCD literature that describes both pain-related barriers to communication and communication-related barriers to pain management (Liederman et al., 2020; Renedo et al., 2019). Though we cannot infer causality from this study, a bidirectional association where communication difficulties both contribute to and result from increase pain severity and interference, is likely. For example, a feedback loop could exist where an AYA with SCD may have health-related communication difficulties which result in more pain and disability, which in turn, results in more communication difficulties. Furthermore, our findings are consistent with models of pain communication, where pain impacts how a patient responds cognitively, emotionally, and behaviourally to the pain, and vice versa (Hadjistavropoulos et al., 2011; Schiavenato & Craig, 2010).

Study limitations should be noted and can inform future directions. First, as this was a cross-sectional study, inferences about causation cannot be made. Longitudinal studies are needed in this area to study changes in the quality of health-related communication and variables of interest over time, as well as predictors of change. Second, our measures of health-related communication were derived from communication subscales embedded within a quality-of-life measure (PedsQL-SCD). As such, this limited our measurement of health-related communication. However, existing measures of health communication are also limited in that they tend to assess communication skills and self-efficacy of the patient (e.g., ability to obtain, understand, and recall information) (Capone & Petrillo, 2014; Clayman et al., 2010) or the provider (e.g., empathy, knowledge, decision-making). There are some measures which assess the strengths and weaknesses of dyadic health communication, such as the Patient-Centred Communication Scale (Moser et al., 2022) and the Patient Assessment of cancer Communication Experiences tool (PACE; Mazor et al., 2016), with items assessing patient perceptions of provider communication efficacy (e.g., fostering healing relationships, responding to emotions, decision-making, enabling self-management). Though these measures were developed with adults only and exclude communication with non-providers, future studies should consider using similar measures that can provide a comprehensive understanding of health communication interactions between AYAs with SCD, providers, and others in their lives. Although the current study represents an important first step in improving our understanding of health communication among AYAs with SCD, a deeper exploration of this construct is warranted given its complexity and the role of multiple actors including parents and providers. As such, future research should use a qualitative or mixed methods approach, utilizing semi-structured interviews, focus groups, live observation, and various self-report measures of health-related communication. The strengths of this study include a focus on AYAs with SCD, who are navigating a unique and challenging developmental period, and our comparison of age groups. We had a large sample size relative to other SCD studies pertaining to health-related communication and pain, which have sample sizes that tend to range from 10-150 (Asnani et al., 2016; Jenerette et al., 2014; Porter et al., 2017; Renedo et al., 2019; Viola et al., 2021b). Finally, we also used validated self-report measures of health-related communication and pain as well as comprehensive medical data extracted from clinical and medical records.

In terms of clinical implications, our results highlight the need to screen for health and pain-related communication difficulties in AYAs with SCD and identify those who may be at increased risk. Interventions to improve communication for AYAs with SCD are needed, particularly for pain management (Collins et al., 2020). Targeted education for healthcare teams and support networks of AYAs with SCD have been shown to improve communication and pain-related outcomes (Asnani et al., 2016; Diniz et al., 2019; Haywood et al., 2011; Haywood et al., 2015; Hood et al., 2021; Smeltzer et al., 2021), but limited provider uptake is a barrier to intervention effectiveness (Shook et al., 2025). Currently, no tailored communication interventions for AYAs with SCD exist (Liederman et al., 2020). However, some related interventions have been tested and show promise. For example, a coaching intervention focused on building patient-provider communication skills for Black veterans with chronic pain showed improved communication self-efficacy and reduced pain and pain interference (Matthias et al., 2024). In SCD, existing interventions like self-management education, transition planning, digital tools, and peer mentoring may increase engagement and self-efficacy among AYAs, in turn supporting communication and optimal pain management (Badawy et al., 2018; Issom et al., 2021; Jean-Baptiste et al., 2022; Plett et al., 2023; Viola et al., 2021a, 2021b).

Conclusion

This work advances our understanding of health-related communication in AYAs with SCD. While most AYAs may readily ask questions and share their feelings with providers, our findings suggest that a notable subset struggle with their pain and disease being misunderstood. Communication difficulties were most pronounced for young adults, and AYAs who were female, had been diagnosed with the Hb SS/Sβ0 genotype, or lived with economic hardship. Elevated pain and pain interference were associated with greater communication difficulties, reinforcing known communication-related barriers in SCD pain management. The current findings provide further support for the routine assessment of pain communication in clinical practice and the development of tailored interventions to equip AYAs and their care networks with the skills to recognize, validate, and respond effectively to SCD pain.

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Table 1. *Demographic and Clinical Characteristics of the Study Population.*

	Overall (N=416)		**Adolescents (N=280)**		**Young Adults (N=136)**		***p*-value**	***q*-value**
	M	***SD***	***M***	***SD***	***M***	***SD***		
Age at study	18.65	2.6	17.2	0.46	21.63	2.64	0.000	0
	n	**%**	***n***	**%**	***n***	**%**		
Sex							1	1
Female	210	50.5	141	50.4	69	50.7		
Male	206	49.5	139	49.6	67	49.3		
Race							1	1
Black	415	99.8	279	99.6	136	100		
White	1	0.2	1	0.4	0	0		
SCD genotype							0.13	0.26
Hb SS/Sβ0	271	65.1	175	62.5	96	70.6		
Non- Hb SS/Sβ0	145	34.9	105	37.5	40	29.4		
Economic Hardship Index								
Very low (0–15.99)	22	5.3	18	6.4	4	2.9	0.58	0.98
Low (16.00–26.99)	87	20.9	60	21.4	27	19.8		
Moderate (27.00–37.99)	153	36.8	103	36.8	50	36.8		
High (38.00–48.99)	121	29.1	78	27.9	43	31.6		
Very High (49.00–100)	33	7.9	21	7.5	12	8.8		
Hydroxyurea[1]								
Yes	201	48.3	121	43.2	80	58.8	0.004*	0.02
No	215	51.7	159	56.8	56	41.2		
Chronic transfusions[1]								
Yes	51	12.3	33	11.8	18	13.2	0.79	1
No	365	87.7	247	88.2	118	86.8		
History of stroke								
Yes	50	12	22	7.9	28	20.6	0.000*	0.002
No	366	88	258	92.1	108	79.4		

Note. M= mean, *SD*= standard deviation, SCD= sickle cell disease. [1]Currently receiving treatment. Q= *q*-value or false discovery rate adjusted *p*-value. *q*<.05. **p*<.05

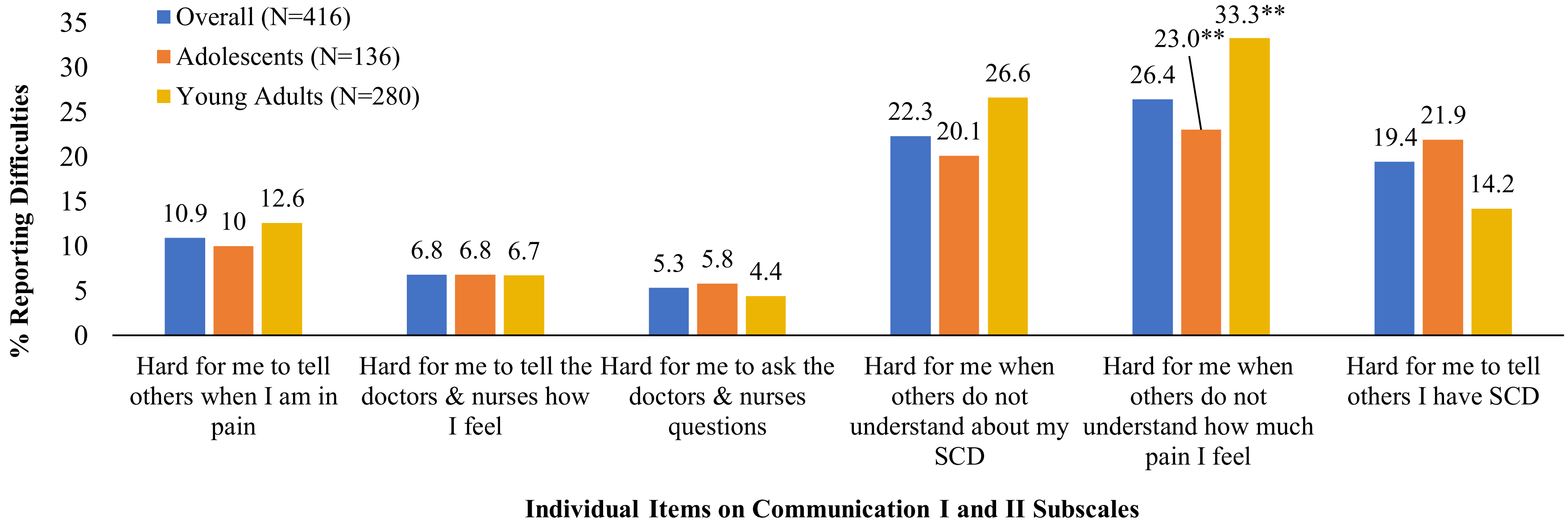
Table 2. *Mean Summary Scores and Distribution of Health-Related Communication Difficulties by Age Group.*

PedsQL-SCD Subscale	**Overall (N=416)**	**Adolescents (N=280)**	**Young Adults (N=136)**	***p*-value**	***q*-value**
	***M* (*SD*)**				
Communication I	20.6 (22.8)	19.9 (23.1)	22.1 (22.3)	0.29	0.59
Communication II	37.2 (28.9)	35.5 (29.9)	40.7 (26.3)	0.03	0.14
	***N* (%)**				
Communication I				0.75	0.96
M< 75	400 (98.0)	269 (96.8)	131 (97.8)		
M> 75	12 (2.9)	9 (3.2)	3 (2.2)		
Communication II				0.96	0.96
M< 75	360 (87.6)	242 (87.4)	118 (88.0)		
M> 75	51 (12.4)	35 (12.6)	16 (11.9)		

Note. M= Mean, *SD*= Standard deviation. *M* ≥75= problems with communication *often* or *almost always*. Q= *q*-value or false discovery rate adjusted *p*-value. *q*<.05. Communication I= self-advocacy, Communication II= eliciting understanding.

Figure 1

Prevalence (%) of Health-Related Communication Difficulties for Individual Items (Score ≥75) by Age Group



Note. ***p*=.03. Item descriptions have been adapted from original version for the purpose of the Figure.

Table 3a. *Associations Between PedsQL-SCD Communication I Subscale and Sociodemographic, Disease, and Treatment-Related Variables.*

Variables	**Overall (N=416)**				**Adolescents (N=280)**				**Young Adults (N=136)**			
	EST	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*
Race (Black)	8.9	23	0.69	0.69	9.60	23.0	0.68	0.86				
EHI Low	4.3	5.4	0.42	0.59	10.0	6.1	0.11	0.33	-20	12	0.10	0.64
EHI Moderate	6.9	5.2	0.18	0.54	13.0	5.8	0.02*	0.22	-18	11	0.12	0.64
EHI High	8.4	5.3	0.11	0.46	12.0	6.0	0.05*	0.22	-11	12	0.34	0.84
EHI Very High	5.4	6.3	0.39	0.59	8.6	7.4	0.25	0.56	-14	13	0.28	0.84
Hydroxyurea[1]	1.1	2.5	0.66	0.69	0.94	3.00	0.76	0.86	1.40	4.30	0.74	0.80
Chronic transfusions[1]	1.6	3.5	0.66	0.69	1.00	4.50	0.82	0.86	3.60	5.80	0.54	0.80
History of stroke (yes)	2.4	3.5	0.49	0.68	2.10	5.20	0.69	0.86	3.1	4.8	0.52	0.86

Note. Multivariate analyses adjusted for age, sex, and genotype. EHI= Economic Hardship Index. EST= estimate, SE= standard error. P= *p*-value. Q= *q*-value or false discovery rate adjusted *p*-value. q=<.05. *$p \leq .05$. [1]Currently receiving treatment. See the Appendix for univariate associations. Communication I= self-advocacy.

Table 3b. *Associations between PedsQL-SCD Communication II Subscale and sociodemographic, disease, and treatment-related variables.*

Variables	Overall (N=416)				Adolescents (N=280)				Young Adults (N=136)			
	EST	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*
Race (Black)	33.0	28.0	0.24	0.56	34.0	30.0	0.25	0.86				
EHI Low	10	6.6	0.13	0.46	14.0	7.8	0.07	0.26	-2.4	14	0.86	0.86
EHI Moderate	2.9	6.3	0.65	0.69	3.5	7.4	0.63	0.82	-2.8	13	0.83	0.86
EHI High	13	6.5	0.04*	0.24	17.0	7.6	0.03*	0.22	3.1	13	0.82	0.86
EHI Very High	17	7.7	0.02*	0.24	20.0	9.5	0.04*	0.22	7.8	15	0.59	0.86
Hydroxyurea[1]	2.40	3.10	0.43	0.66	3.00	3.90	0.44	0.86	1	4.90	0.83	0.83
Chronic transfusions[1]	-5.4	4.40	0.21	0.56	-4.4	5.80	0.45	0.86	-5.9	6.60	0.37	0.80
History of stroke (yes)	-3.7	4.40	0.40	0.66	-4.2	6.70	0.53	0.86	-2.8	5.4	0.6	0.86

Note. Multivariate analyses adjusted for age, sex, and genotype. EHI= Economic Hardship Index. EST= estimate, SE= standard error. P= p-value. Q= q-value or false discovery rate adjusted p-value. q=<.05. *p≤.05. [1]Currently receiving treatment. See the Appendix for univariate associations. Communication II= eliciting understanding.

Table 4. *Associations Between Health-Related Communication and Pain and Pain Interference.*

	Overall (N=416)				**Adolescents (N=280)**				**Young Adults (N=136)**			
	EST	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*
Communication I Subscale												
Pain	0.45	0.04	5.40E-21	1.08E-20	0.47	0.05	4.70E-15	6.27E-15	0.43	0.08	1.60E-07	3.20E-07
Pain Interference	0.41	0.04	9.70E-20	1.29E-19	0.44	0.05	4.00E-15	6.27E-15	0.38	0.08	3.60E-06	4.80E-06
Communication II Subscale												
Pain	0.44	0.06	6.60E-13	6.60E-13	0.48	0.07	2.20E-09	2.20E-09	0.38	0.09	6.30E-05	6.30E-05
Pain Interference	0.53	0.05	1.20E-20	1.92E-20	0.57	0.06	2.20E-15	4.40E-15	0.45	0.09	2.10E-06	3.36E-06

Note. Multivariate analyses adjusted for age, sex, and genotype. EST= estimate, SE= standard error. P= *p*-value. Q= *q*-value or false discovery rate adjusted *p*-value. Q= *q*-value or false discovery rate adjusted *p*-value. *q*=<.05. Communication I= self-advocacy, Communication II= eliciting understanding.

Appendix

Supplemental Table 1. *Univariate Associations Between PedsQL-SCD Communication I Subscale and Sociodemographic, Disease, and Treatment-Related Variables.*

Variables	**Overall (N=416)**				**Adolescents (N=280)**				**Young Adults (N=136)**			
	EST	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*
Age	0.35	0.43	0.42	0.52	1.0	3.0	0.73	0.91	0.02	0.74	0.97	0.97
Sex (Female)	7.80	2.20	0.0005*	0.004	6.80	2.70	0.01*	0.14	9.90	3.80	0.009*	0.08
Genotype (Hb SS/Sβ0)	3.00	2.40	0.20	0.33	4.30	2.90	0.14	0.45	-0.42	4.30	0.92	0.97
Race (Black)	12.0	23.0	0.59	0.65	12.0	23.0	0.62	12.0				
EHI Low	4.2	5.5	0.44	0.55	10.0	6.2	0.09	0.25	-22.0	12.0	0.06	0.35
EHI Moderate	7.3	5.2	0.16	0.34	14.0	5.9	0.02*	0.12	-20.0	12.0	0.09	0.40
EHI High	8.6	5.3	0.1	0.28	13.0	6.0	0..03*	0.12	-14.0	12.0	0.22	0.66
EHI Very High	6.6	6.3	0.3	0.48	12.0	7.5	0.18	0.36	-15.0	13.0	0.24	0.66
Hydroxyurea[1]	1.80	2.30	0.42	0.52	2.00	2.80	0.48	0.80	0.54	3.90	0.89	0.97
Chronic transfusions[1]	3.10	3.40	0.36	0.51	3.80	4.30	0.38	0.69	1.70	5.70	0.76	0.97
History of stroke (yes)	4.40	3.40	0.20	0.33	4.70	5.10	0.36	0.69				

Note. Multivariate analyses adjusted for age, sex, and genotype. EHI= Economic Hardship Index. EST= estimate, SE= standard error. P= *p*-value. Q= *q*-value or false discovery rate adjusted *p*-value. *q*=<.05. *$p \leq .05$. [1]Currently receiving treatment. Communication I= self-advocacy.

Supplemental Table 2. *Univariate Associations Between Pedsql-SCD Communication II Subscale and Sociodemographic, Disease, and Treatment-Related Variables.*

Variables	**Overall (N=416)**				**Adolescents (N=280)**				**Young Adults (N=136)**			
	EST	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*	*EST*	*SE*	*P*	*Q*
Age	1.10	0.55	0.05*	0.14	0.56	3.90	0.89	0.99	0.89	0.86	0.30	0.77
Sex (Female)	11.0	2.80	0.0002*	0.003	8.10	3.60	0.02*	0.15	16	4.30	0.0003*	0.007
Genotype (Hb SS/Sβ0)	7.80	3.00	0.009*	0.04	7.80	3.70	0.03*	0.15	6.7	4.90	0.18	0.64
Race (Black)	37.0	29.0	0.20	0.33	36.0	30.0	0.23	0.51				
EHI Low	11	6.8	0.12	0.28	15.0	7.9	0.06	0.19	-6.6	14	0.64	0.97
EHI Moderate	4.4	6.5	0.5	0.6	4.6	7.5	0.54	0.72	-4.9	14	0.72	0.97
EHI High	15	6.6	0.02*	0.12	18.0	7.7	0.02*	0.12	-1.5	14	0.91	0.97
EHI Very High	19	7.9	0.01*	0.09	21.0	9.5	0.03*	0.12	6.3	15	0.68	0.97
Hydroxyurea^1	5.00	2.80	0.07	0.19	5.0	3.60	0.17	0.45	3.3	4.6	0.48	0.81
Chronic transfusions^1	-1.30	4.30	0.77	0.77	0.66	5.60	0.91	0.99	-5.3	6.7	0.42	0.81
History of stroke (yes)	1.30	4.40	0.77	0.77	0.08	6.70	0.99	0.99				

Note. Multivariate analyses adjusted for age, sex, and genotype. EHI= Economic Hardship Index. EST= estimate, SE= standard error. P= p-value. Q= q-value or false discovery rate adjusted p-value. q=<.05. *$p \leq .05$. ^{1}Currently receiving treatment. Communication II= eliciting understanding.