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Peer Support in Adolescents Hospitalized for Sickle Cell Pain Crises

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PEER SUPPORT IN ADOLESCENTS HOSPITALIZED FOR SICKLE CELL PAIN CRISES

by

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Under the Direction of Lindsey Cohen, PhD

ABSTRACT

Sickle cell disease (SCD) is an inherited blood disorder, which has a range of symptoms including pain, fatigue, organ damage, and immunodeficiency. Patients are commonly hospitalized for SCD-related difficulties, most frequently for vaso-occlusive pain crises. In other illness populations, social support has served as a protective factor and aspects of social support (e.g., type of peers and communication) may have differential benefits. The overall aim of this study was to examine pain, social support, type of friend communication, similarity of friends, perceived stigma, quality of life, and loneliness in adolescents admitted to the hospital for SCD pain crises. Perceived social support predicted decreased loneliness in the hospital but did not mediate the relation between pain and loneliness or pain and quality of life. Stigma emerged as a consistent predictor of negative outcomes in terms of quality of life, loneliness, and reduction of pain in the hospital. Qualitative data revealed that hospitalization may have neutral, beneficial and negative effects on friendships and these effects may be dependent on how friends react during pediatric patients' hospitalizations.

INDEX WORDS: Adolescents, Pain, Sickle Cell Disease, Social Support

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DEDICATION

First and foremost, I dedicate this dissertation to the children and adolescents living with sickle cell disease. Their strength and knowledge inspired this project and I can only hope that this work benefits them as much as I have learned from their insights. I would also like to dedicate this dissertation to my family and friends for their unwavering support and encouragement throughout this process. I would not be where I am today without their loving guidance and patience. Lastly, I dedicate this work to my dear friend, Ben Carlson, whose faith in my determination will continue to be a source of inspiration.

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1 INTRODUCTION

Sickle cell disease (SCD) is an inherited blood disorder, which has a range of symptoms including pain, fatigue, organ damage, and immunodeficiency. Although mild symptoms are largely managed at home, patients are commonly hospitalized for SCD-related difficulties, most frequently for vaso-occlusive crises, or "pain crises." On average, youth with SCD are hospitalized two times annually (Sobota, Graham, Neufeld, & Heeney, 2012). Symptom-related restrictions on activities and perceived stigma about the disease can lead to diminished quality of life and loneliness, especially for hospitalized youths. In other illness populations, social support has served as a protective factor (Dennis, 2003; La Greca et al., 1995; Uchino, 2006). The overall aim of this study is to examine social support, type of peer communication (e.g., in-person, electronic media), similarity of peers (i.e., whether peers have a similar health status), perceived stigma, quality of life, loneliness, hospital pain, and length of hospital stay in adolescents admitted to the hospital for sickle cell pain crises.

1.1 Overview of Sickle cell Disease

SCD is one of the most common monogenic disorders and it affects primarily individuals of African, South or Central American, Caribbean, or Mediterranean decent. Based on United States birth cohort disease prevalence, approximately 119,000 individuals are born with SCD and roughly 70-99% of these individuals are African American (Hassell, 2010a). It is estimated that there are up to 5,000 individuals living with SCD in the state of Georgia (Hassell, 2010b).

SCD primarily affects hemoglobin, which delivers oxygen throughout the body. Sickle hemoglobin causes individuals with SCD to have distorted, sickle- or crescent-shaped red blood cells. These blood cells tend to break down prematurely and, unlike typical red blood cells, are stiff and tend to stick to other cells, which can block blood flow to organs and other parts of the

body. Cell inflexibility results in many unfortunate complications. “Sickle cell anemia” is one of approximately ten sickle cell genotypes and accounts for 70% of sickle cell disease cases (Rees, Williams, & Gladwin, 2010). Sickle cell anemia, or HbSS, has a more severe clinical presentation and is caused by a mutation of the homozygote for the β-globin. HbS^0 beta thalassemia is less common but also a more severe genotype and caused by a double heterozygote for HbS and $beta^0$ (Rees et al., 2010; Yawn, Buchanan, Afenyi-Annan, et al., 2014). Hemoglobin SC, or HbSC, is a more moderate form of the disease and accounts from 25-30% of cases in populations from African origin (Nagel, Fabry, & Steinberg, 2003). HbS beta+ thalassemia has a mild to moderate clinical presentation with variable prevalence across different ethnic groups (Rees et al., 2010).

Over the last 50 years, improvements in screening and treatment has resulted in improved survival rates for individuals with SCD, with the average life expectancy increasing from 20 years to approximately 38-48 years (Lanzkron, Carroll, & Haywood, 2013; Platt et al., 1994). Despite improvements in treatment, individuals with SCD continue to experience a variety of acute and chronic symptoms. Most SCD-related symptoms and complications are directly or indirectly related to the vascular system and the deficiency and/or abnormality of hemoglobin. Common complications include acute chest syndrome (i.e., inflammation, infiltration and loss of oxygen in the lungs), reduced organ function, immunodeficiency, stroke, fatigue, shortness of breath, priapism (i.e., persistent and painful erection), and acute and chronic pain as a result of vaso-occlusion.

1.2 Pain in Pediatric Sickle Cell Disease

Pain is the primary SCD-related symptom and unpredictable and recurrent vaso-occlusive pain episodes (i.e., “pain crises”) are often the most debilitating symptom of SCD. Vaso-

occlusive episodes (VOEs) occur when red and white blood cells become entangled, which results in vascular blockage, inflammation, restriction of blood supply to tissues, and significant pain. Pain is the leading cause of healthcare utilization and morbidity in individuals with SCD (Smith & Scherer, 2010; Yawn et al., 2014) and can occur as early as six months following birth and is the most common complication in children with SCD (Chiang & Frenette, 2005; Dampier et al., 2010). In a large prospective pediatric study, data indicated that half of patients with HbSS experienced a VOE before the age of five (Gill et al., 1995).

Beyond the physical discomfort, pain impacts functioning across nearly all facets of life. Specifically, children and adolescents with pain conditions report moderate to high functional disability and pain-related interference on physical, psychological, and social functioning (Gauntlett-Gilbert & Eccleston, 2007; Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001; Varni et al., 2010) and decreased quality of life (Huguet & Miro, 2008; Palermo, 2000; Sawyer et al., 2004). Within the sickle cell population, pain symptomatology interacts with psychosocial factors and quality of life (Dampier et al., 2010; Edwards et al., 2005; Gil, Abrams, Phillips, & Keefe, 1989; Gil et al., 2001). Dampier et al. (2010) reported that a large sample of children with SCD not only had diminished quality life, but those who had at least one hospitalization in the last two years reported significantly lower quality of life. In a longitudinal study, Schlenz, Schatz, McClellan, and Roberts (2012) reported that frequency of pain episodes from pre- to post-time points predicted declines in health related quality of life. It is evident that complications from sickle cell pain often result in decreased school attendance, poor social functioning, and overall poor psychological adjustment in children, which can result in further negative outcomes throughout childhood and into adolescence (Edwards et al., 2005; Gil et al., 1993, 1989).

1.3 Hospitalizations in Pediatric Sickle Cell Disease

Severe pain experienced by individuals with SCD often results in hospitalizations, which can further limit quality of life (Burlew, Telfair, Colangelo, & Wright, 2000). A large multisite study indicated that over a thirty month period, 12,104 children with SCD were hospitalized for VOE with an average length of stay of 3.6 ± 2.3 days (Sobota et al., 2012). Data revealed that 17 percent of these children were readmitted to the hospital in 30 days and 51 percent of the sample had two or more readmissions over the course of the study period. Another large, nationwide study reported a slightly longer average length of stay for VOE hospitalization (i.e., 4.4 days) and reported that increased length of stay was associated with older age (Panepinto et al., 2005).

It is evident that children with SCD are at an increased risk of repeated inpatient hospitalizations, which, given the often unexpected nature of pain episodes, can result in fear, loneliness, and increased separation from their daily lives and loved ones. Indeed, research on pediatric hospitalizations has shown that inpatient admissions are stressful and anxiety provoking for children (Boyd & Hunsberger, 1998; Wilson, Megel, Enenbach, & Carlson, 2010; Ziegler & Prior, 1994). The majority of children experience significant anxiety, and homesickness can spike during admissions (Lambert, Coad, Hicks, & Glacken, 2013; Thurber, Patterson, & Mount, 2007; Wilson et al., 2010).

Repeated or lengthy hospital stays can contribute to feelings of loneliness (Lambert et al., 2013) and in one adult study repeated medical visits and pain crises predicted increased feelings of loneliness in patients with SCD (Asnani, Fraser, Lewis, & Reid, 2010). Qualitative research also indicates that adolescents with chronic pain endorse often feeling lonely and unsupported by peers (Forgeron, Evans, McGrath, Stevens, & Finley, 2013). Loneliness can lead to further adverse outcomes and has been shown to be related to poor physical and psychological outcomes

and morbidity and mortality (Hawkley & Cacioppo, 2010; Holt-Lunstad, Smith, & Layton, 2010). A recent longitudinal study found that perceived social isolation in childhood predicted poor health outcomes in adulthood after controlling for childhood risk factors for poor adult health, health damaging behaviors, and exposure to stressful life events (Caspi, Harrington, Moffitt, Milne, & Poulton, 2006). Further, the authors reported that chronic social isolation throughout childhood had a cumulative influence on poor adult health outcomes (Caspi et al., 2006). Thus, feelings of loneliness may have an additive effect and result in negative long-term consequences.

1.4 Social Support and Health

Research on social support gained prominence in the 1970's and 1980's. Though researchers did not present a consistent conceptualization or agreed-upon operational definition of social support, defining factors often included the quantity and/or quality of social relationships. Lowenthal and Haven (1968) defined social support as the presence or absence of an intimate partner; Cobb (1976) operationalized the concept of social support as information leading an individual to believe that she or he is loved, valued, and a member of a network; Kaplan et al. presented that support is the extent to which an individual's needs for belonging, affection, approval and security are met by others; Lin et al. (1981) conceptualized social support as the availability of individuals and resources in a crisis; and House (1981) defined social support as an interpersonal transaction including emotional concern, instrumental aid, information and/or appraisal. Overall, a multidimensional conceptualization of social support is generally accepted and researchers have identified defining attributes of social support, which include emotional (affective assistance), instrumental (tangible and informational aid), and appraisal support (affirmational communication; Barrera Jr, 1986; House, 1981; Tilden & Weinert, 1987).

As a conceptualization of social support developed, researchers demonstrated that social support predicted improved health outcomes and proposed that social support served as a physical and psychological protective factor (Caplan, 1974; Cassel, 1976; Cobb, 1976; House, Landis, Umberson, & others, 1988; Lowenthal & Haven, 1968). Subsequent prospective longitudinal studies in the United States (Berkman & Syme, 1979; House, Robbins, & Metzner, 1982; Schoenbach, Kaplan, Fredman, & Kleinbaum, 1986), Finland (Kaplan et al., 1988), and Sweden (Welin et al., 1985) suggested that limited numbers of social relationships and less communication with friends predicted mortality.

This research led researchers to propose main effect and stress-buffering effect models of social support (Cohen & Wills, 1985). The main effect model proposes that support received from social relationships has a direct effect on well being regardless of the presence of a stressor. Within this model, social relationships and networks affect health outcomes through social influence and integration (Berkman, Glass, Brissette, & Seeman, 2000; Cohen, Gottlieb, & Underwood, 2000). Within the stress-buffering model, support received from social relationships modulates responses to negative life events and prevents potential negative psychosocial or physical outcomes (Broadhead et al., 1983; Cohen et al., 2000; Cohen & Wills, 1985; House et al., 1988; Kawachi & Berkman, 2001). Thus, support is beneficial to individuals that are experiencing stress.

Wills and Bantum (2012) proposed that social support contributes to resiliency in individuals who are faced with negative life events and data indicate that peer social support can help buffer the negative impacts of illness and stressors (Thoits, 2011; Uchino, 2006; Uchino, Cacioppo, & Kiecolt-Glaser, 1996; Wills & Bantum, 2012). It was further hypothesized that support from social relationships promotes good self-control or self-regulation in adolescents,

which, in turn, is related to development of positive attitudes and competencies. Similarly, social networks that consist of meaningful and reciprocal relationships can positively influence engagement in overall health behavior, enhance coping with a medical illness, and shape beneficial health care behaviors (Berkman et al., 2000; Pescosolido & Levy, 2001; Pescosolido, 1996; Thoits, 2010).

Within a health care context, Dennis (2003) defined peer support similarly and added that support is received by a "social network member who possesses experiential knowledge of a specific behavior or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person" (p. 329). Based on an extensive literature review, Dennis further proposed that support from peers positively influences psychological and physical health outcomes through directly influencing health outcomes (i.e., direct effect model), protecting individuals from stressful events (i.e., buffering effect model), and intervenes indirectly to influence health through behaviors, emotions and cognitions (i.e., mediating model; Figure 1).

1.5 Form and Function of Social Support

In the adult literature, researchers report a consistent positive relation between social support and health outcomes; however, little is known about whether unique aspects of social support or other variables influence the nature of support received and the relations among support, health, and quality of life. The type of interactions and the characteristics of those providing support in an individual's social network may help better explain this relation (Dennis, 2003; Kyng 2004; Thoits, 2011). Specifically, Thoits proposed that individuals can receive added and possibly better coping assistance from experientially similar others or those who have had similar experiences (e.g., also have a chronic illness). Experientially similar others may

provide more specialized support through empathic understanding, relevant information or advice, role modeling, inspirational hope, education about coping strategies, social comparison, or altering threat/stressor interpretation. In a review of peer support interventions, Dennis (2003) highlighted the importance of considering antecedents to the provision of social support and argued that a shared experiential knowledge of a health-related situation is needed to ensure a supportive relationship. A recent study suggested that the added benefit of similar others examined network ties among parents of pediatric cancer patients and found that relationships with other families who had children diagnosed with cancer positively influenced coping, problem solving, hope, and health care behavior (Gage, 2013). Similarly, the added benefits of support from experientially similar peers was also found in a studies that examined social support in individuals living with HIV (Peterson, Rintamaki, Brashers, Goldsmith, & Neidig, 2012), diabetes (Heisler, 2009), kidney disease (Hughes, Wood, & Smith, 2009), and mothers managing postnatal depression (Dennis et al., 2009).

In an effort to describe how social support functions for individuals with chronic health conditions, Frohlich (2014) recently proposed a model of social support that emphasizes the importance of examining an individual's 'social environment' as opposed to their social network (Figure 2). In contrast to a social network, a social environment includes peers that an individual talks to about his/her health condition. The proposed social support model for people with chronic health conditions (Frohlich, 2014) seeks to examine how individuals in need of support seek support from members of their social environment over time depending on their health status (e.g., symptom changes, admission to the hospital). Within this model, health impact, difficulty of treatment, and change over time influence patients' social support needs and how they seek out those needs, which then influence emotional and behavioral outcomes. Thus social

support mediates the relation between an illness-related need for support (e.g., pain) and outcomes. Further, Frohlich proposed a call for researchers to examine individuals' complete social support environment, how their support needs differ depending on health status, and whether emotional and behavioral outcomes are affected by a change in health status and/or support.

1.6 Social Support and Adolescence

Social functioning and support are particularly important during adolescence as socialization plays an important role in development and, in contrast to friendships in childhood, adolescent friendships are marked by increased self-disclosure and intimacy (Buhrmester, 1990; Shaffer, 2008). Adolescent development is marked by influential exchanges between the developing individual and the social context and adolescents are more highly peer-focused and gain insight into their social environment via peer interactions (Lerner & Steinberg, 2009). The individual function of socialization promotes interpersonal differentiation and an autonomous self, whereas the social function encourages integration, which facilitates connection with others (Adams & Marshall, 1996). These processes work together to support healthy identity and self-esteem development and they cannot progress in isolation (Adams & Marshall, 1996; Damon, 1983; Handel, 2006). Socialization also meets the need for a sense of belonging (Adams & Marshall, 1996; Josselson, 1987; Sampson, 1989), which is positively associated with psychological well-being (Baumeister & Leary, 1995). Similarly, neuroimaging studies have identified that brain regions associated with emotion regulation and self-development mature through social experiences and connections with peers and these brain regions are more engaged in adolescents (Pfeifer & Peake, 2012). Taken together, adolescents meet individual, social, and neurological developmental needs within the context of their peers.

Overall, perceptions of intimacy and closeness within friendships for both boys and girls increase during adolescence, but gender similarities and differences have been reported in social support literature (Shaffer, 2008). Studies report that girls tend to engage in more self-disclosure and report more intimacy in relationships (Rose & Asher, 2004; Rubin et al., 2004) and have been shown to report more support from friends and classmates (Bokhorst, Sumter, & Westenberg, 2010; Cheng & Chan, 2004); however, other research indicates that these differences do not always exist and some authors argue that the way closeness is defined and conceptualized in child and adolescent studies may be bias towards a more feminine manner (i.e., measure self-disclosure and emotional expressiveness) (Bagwell & Schmidt, 2013; Hartup & Stevens, 1997). For example, friendship quality tends to be higher for girls when closeness, empathic understanding and intimacy are measured whereas limited gender differences are reported when sharing activities and companionship are measured (Bukowski, Hoza, & Boivin, 1994; Furman & Buhrmester, 1985; Parker & Asher, 1993). Other studies have shown that friendship quality does not differ among boys and girls (Brendgen, Markiewicz, Doyle, & Bukowski, 2001). How adolescents utilize support to cope may differ among boys and girls, with boys tending to use more avoidance of socializing as a coping strategy whereas girls tend to seek out peer support for coping (Eschenbeck, Kohlmann, & Lohaus, 2007).

1.7 Social Support in Pediatric Sickle Cell Disease

Haas, Schaefer, and Kornienko (2010) examined the bidirectional pathways linking social networks and health in adolescents in the United States and reported that health status can shape social networks. The authors identified health condition as a central adolescent characteristic that influences social position. Poor self-reported health status predicted social isolation, smaller

network size, and weaker friendships. It was also reported that older adolescents and African American adolescents had smaller network densities and interconnectedness among peers.

SCD-related pain and hospitalizations and can restrict the ability and opportunity to participate in social activities, which may result in further feelings of loneliness and other harmful outcomes. Although studies to date have not directly examined perceived social support and loneliness in adolescents with SCD, a recent review of social functioning and peer relationships in children and adolescents with pain conditions, including SCD, concluded that children with pain conditions were less well liked than their peers and were viewed as more isolated (Forgeron et al., 2010). Similarly, children and adolescents with SCD are perceived as less popular and have fewer friends than their peers (Noll, Kiska, Reiter-Purtill, Gerhardt, & Vannatta, 2010; Noll, Reiter-Purtill, Vannatta, Gerhardt, & Short, 2007). Youths with SCD also report more social problems, limitations in their peer activities, and difficulty taking part in social activities (Fuggle, Shand, Gill, & Davies, 1996; Tonya Palermo, Schwartz, Drotar, & McGowan, 2002; Rodrigue, Streisand, Banko, Kedar, & Pitel, 1996). Taken together, health status may influence social functioning and isolation, and limited or avoided social interactions as a result of disease symptoms and hospitalizations may have a negative impact on adolescents' supportive environment and overall quality of life.

1.8 Communication and Social Support

In the United States, children use digital media approximately six to seven hours per day (Rideout, Foehr, & Roberts, 2010) and 90 percent of adolescents and young adults are regular internet users (Lenhart, Purcell, Smith, & Zickuhr, 2010); however, little is known about how different forms of communication (e.g., in-person, texting, electronic media communication) might differentially influence support received from peers in children with chronic illnesses.

Research reports conflicting results on the potential benefits of online communication. Some literature favors the *reduction* hypothesis, which proposes that communication with new online friends thwarts existing friendships (Locke, 1998). In fact, data indicate that face-to-face, in-person communication may predict increased positive social well-being whereas online communication has no association to social well-being (Pea et al., 2012). In contrast, the opposing *stimulation* hypothesis states that limited audio and visual cues encourage self-disclosure among friends, which then enhances closeness among existing friendships (Bargh & McKenna, 2004; Leung, 2002; McKenna, Green, & Gleason, 2002; Valkenburg & Peter, 2007). Surveys conducted on young adult and adult samples report that increased internet use was either associated with improved psychosocial outcomes and more time spent with family and friends (Kraut et al., 2002) or internet usage did not result in less time spent with friends or family (Nie & Erbring, 2000). Other data indicate that internet communication may help maintain long distance relationships (Wellman, Haase, Witte, & Hampton, 2001) and strengthen offline relationships with friends (Reich, Subrahmanyam, & Espinoza, 2012). Further, Facebook usage in young adults has been shown to be related to increased social capital, or offline social benefits (Steinfield, Ellison, & Lampe, 2008), and predict decreased loneliness and increased social adjustment (Yang & Brown, 2013).

Research on healthy populations produces somewhat conflicting results about the influence of electronic media communication on friendships and support; however electronic forms of communication (e.g., Facebook messaging and texting) may be beneficial to children with illnesses or who are hospitalized and are restricted in their ability to participate in social activities or in-person interactions. Thus, within the framework of Frohlich's (2014) model of social support (Figure 2), change in health status (e.g., hospitalization) may influence how

adolescents seek support and communicate with members of their supportive environment, which may further influence outcomes such as loneliness and quality of life.

1.9 Stigma and Social Support

SCD health-related stigma may also influence access to support and exacerbate psychosocial factors such as loneliness and quality of life in individuals with SCD. Adolescents with SCD may differ from other individuals with pain conditions in that they may experience added stress associated with ethnic disparities in the health care system and the potential stigma associated with SCD. Health-related stigma is defined as an experienced or anticipated social process characterized by rejection, devaluation, or judgment of individual based on his or her health (Weiss, Ramakrishna, & Somma, 2006). For individuals with SCD, health-related stigma can begin in childhood and present a challenge into and through adulthood (Jenerette & Brewer, 2010).

SCD-related stigma can originate from experiences with health care providers, peers, teachers, or community members and is said to stem from the history of the discovery and perception of the disease in American culture in which it was associated with the promotion of White genetic superiority and labeled as “bad blood” within African American communities (Jenerette & Brewer, 2010; Savitt, 1981; Smith, Oyeku, Homer, & Zuckerman, 2006; Wailoo, 2001). In countries with more limited resources (i.e., sub-Saharan African countries), lack of knowledge about SCD, misunderstanding of the disease, and little government support all further perpetuate SCD-related social stigma (Odame, 2014). To date, families of children with SCD endorse fears of stigmatization as a result of inaccurate assumptions about SCD, which include beliefs that is it contagious, it is a curse, and that the mother knew of her SCD trait status and intentionally conceived an ill child (Burnes, Antle, Williams, & Cook, 2008). Qualitative

research has revealed that mothers of children with SCD have reported feeling isolated and have endorsed refraining from disclosing their child's sickle-cell status to other families as a result of anticipated stigmatization (Burnes et al., 2008). Children with SCD have also endorsed refraining from disclosing their sickle-cell status to their peers as a result of anticipated stigmatization (Burnes et al., 2008). In addition, SCD-related stigma has been shown to influence social isolation, self-esteem, depression, and disease management in adult patients (Jenerette, Brewer, Edwards, Mishel, & Gil, 2014; Jenerette, Funk, & Murdaugh, 2005; Jenerette & Brewer, 2010). Research examining other stigmatized chronic health conditions (e.g. HIV) has reported similar finding which indicate that health-related stigma predicts access to support (Mak et al., 2007; Quinn & Earnshaw, 2011; Smith, Rossetto, & Peterson, 2008).

Further, literature consistently reports an unfortunate under-treatment of pain among patients who are members of underrepresented racial and ethnic groups, with Hispanic or African American patients receiving inadequate pain treatment (Green et al., 2003). Although pain is the hallmark symptom of SCD; data indicate that patients with SCD are undertreated for pain, which might be partially related to their race and thus result in added perceived stigma (Benjamin et al., 1999; Green et al., 2003). Indeed, in qualitative studies, racism was perceived as underlying factor in disparities in SCD-related care (Burnes et al., 2008).

Taken together, individuals with SCD may receive unequal health care as a result of their minority status, which may lead to an increased need for support. Unfortunately, individuals' perceived stigma might also result in avoidance of others or isolation and thus hinder their ability to disclose a need for support and form supportive social networks.

1.10 Summary and Aims

In summary, SCD is associated with frequent pain and hospitalizations, which can result in diminished quality of life and loneliness. The extant literature suggests that social support may

mediate these relations, however, no studies to date have examined the nature of social support and the social environment (e.g., similarity of friends, in-person and electronic media communication) in relation to outcomes within this population. Additionally, studies that have assessed social support in pediatric pain populations thus far have examined social functioning and participation in social activities without assessing perceived social support from friends. Further, there are no data to indicate whether stigma might influence social support and psychosocial outcomes in a pediatric SCD population. Thus, in line with Frohlich's (2014) call for researchers to examine an individual's social environment and how aspects of perceived support and health status may influence outcomes, the primary aim of this study was to describe and examine the relations among demographic variables, pain, perceived social support, similarity of friends (i.e., whether friends have a similar health status), type of friend communication (e.g., in-person or electronic media), and perceived stigma, and if these factors predict quality of life and loneliness in adolescents hospitalized for SCD pain crises. Further, as proposed in Frohlich's (2014) social support model, secondary aims included an examination of whether psychosocial outcomes (i.e., quality of life and loneliness) were associated with health outcomes while hospitalized (i.e., decrease in pain and length of hospital stay).

Past research indicates that having similar friends, forms of communication, and stigma may influence and hinder access to support (Smith et al., 2008; Thoits, 2011; Yang & Brown, 2013). Thus, exploratory aims included an examination of (a) whether stigma moderates the association between pain and social support, (b) whether having friends with SCD moderates the association between pain and social support, (c) whether communication moderates the association between pain and social support, and (d) qualitative assessments of adolescents' perception of how hospitalization influences their peer relationships and communication. Given

that past research has proposed both mediating (Dennis, 2003; Frohlich, 2014) and moderating (Cohen & Wills, 1985; Dennis, 2003) models of social support and health symptoms (e.g., pain) and minimal evidence exists on the relations among perceived support and outcomes in pediatric sickle cell populations, additional exploratory analyses will test whether (a) social support mediates the relation between pain and the psychosocial outcomes and/or (b) social support moderates the relation between pain and the psychosocial outcomes.

1.10.1 ***Hypotheses***

I hypothesized that significant relations would exist among pain, support, similarity of peers, type of communication, and perceived stigma, and outcomes (i.e., quality of life and loneliness) variables. Specifically, I hypothesized that increased social support and similarity of peers would predict higher quality of life and less loneliness. Given that hospitalizations may restrict opportunities for in-person social interactions and literature suggests that electronic communication may help maintain relationships and result in decreased feelings of loneliness (Bargh & McKenna, 2004; Wellman et al., 2001; Yang & Brown, 2013), I hypothesized that more electronic media communication would predict more support, higher quality of life, and less loneliness. Consistent with other studies assessing effects of stigma in adults with SCD (Jenerette & Brewer, 2010), I hypothesized that higher perceived stigma would predict less support, lower quality of life, and more loneliness. For secondary aims in line with Frohlich's model, I hypothesized that higher quality of life would be associated with greater reductions in pain while in the hospital and a shorter length of stay. Similarly, I hypothesized that lower loneliness would be associated with greater reductions in pain and a shorter length of stay.

For the quantitative exploratory aims, I hypothesized that stigma, communication, and having friends with SCD would moderate the association between pain and social support.

Specifically, in line with literature indicating that individuals with high perceived stigma may have more difficulty seeking support (Smith et al., 2008), I hypothesized that, at high levels of stigma, pain would predict significantly lower social support than at low levels of stigma. In addition, in line with the stimulation hypothesis (Valkenburg & Peter, 2007), I hypothesized higher pain would predict more social support only at high levels of both in-person and electronic communication. Considering that experientially similar others may provide more specialized support (Thoits, 2011), having friends with SCD would buffer the association between pain and social support such that when adolescents have friends who also have SCD, pain would not predict lower social support. Finally, given that research supports the mediation and moderation models of social support, I hypothesized that social support would mediate and moderate the relations between pain outcomes. Figure 3 displays the study aims and hypotheses.

Provider	**Defining Attributes**	**Effect Model**	**Potential Health Outcomes**
PEERS →	Emotional Support Appraisal Support Informational Support →	Direct Buffering Mediating →	Augmenting Social Network Preventing Health Concerns Reinforcing Help-Seeking Behaviors Decreasing Barriers to Care Encouraging Effective Coping Promoting Social Comparisons Increasing Self-Efficacy Aiding Self-Esteem

Figure 1. Dennis Peer Support Model

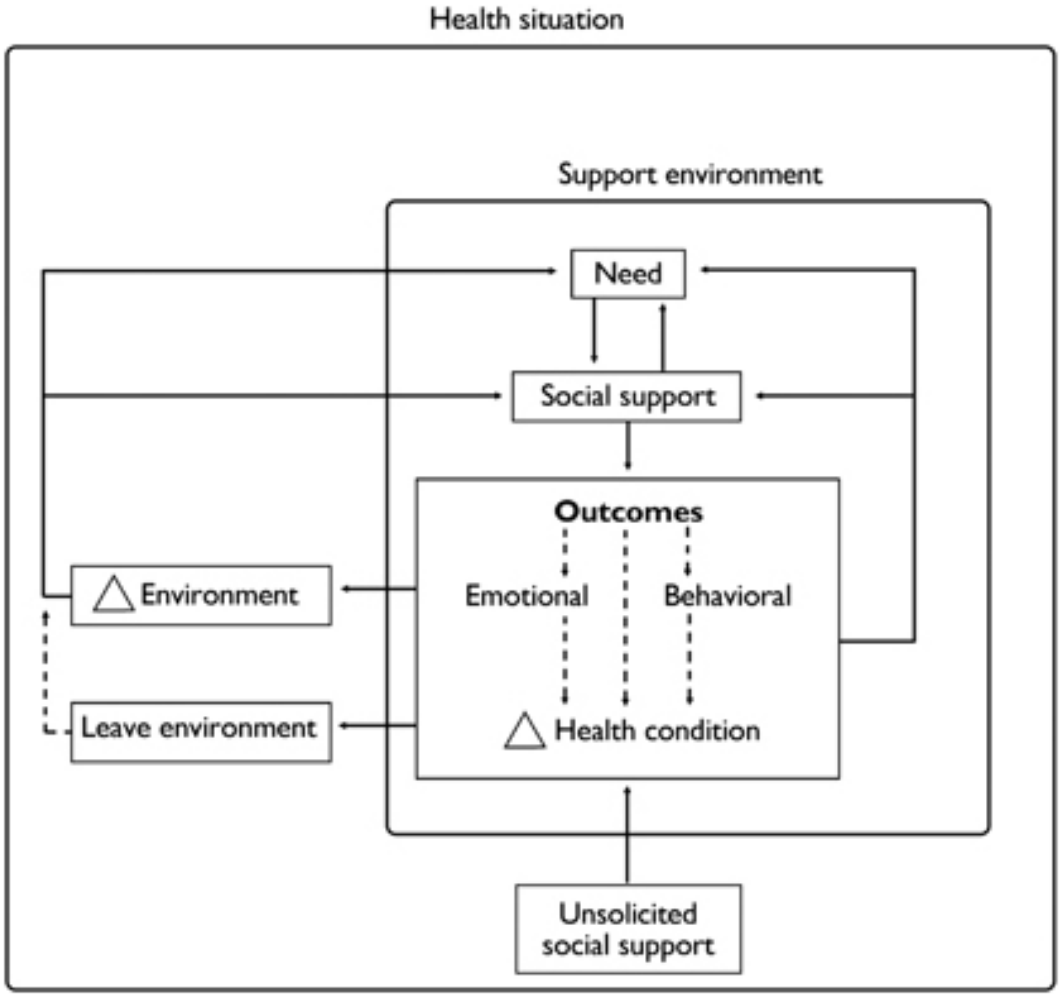


Figure 2. Frohlich's Social Support Model for People with Chronic Health Conditions

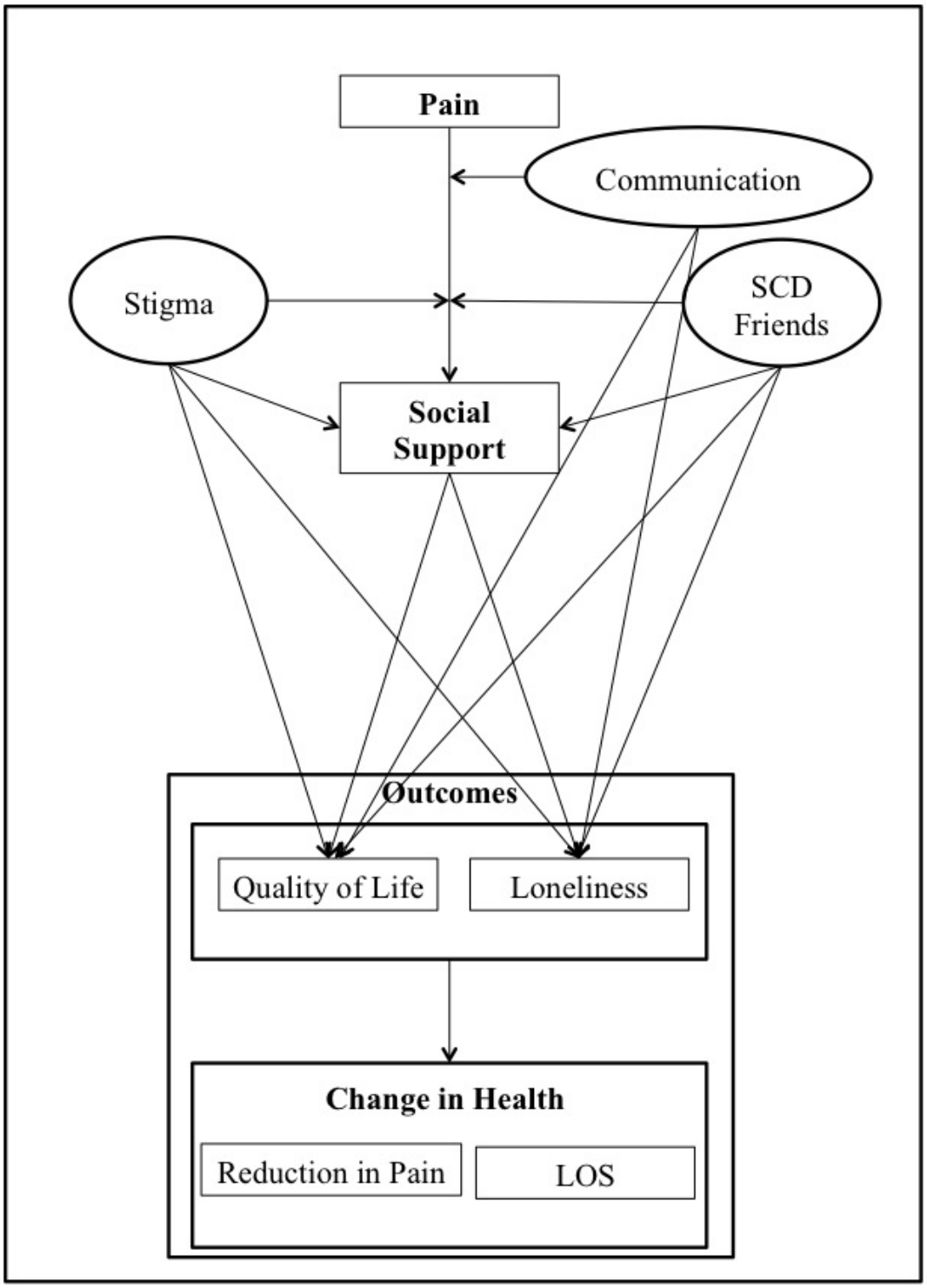


Figure 3. Study Hypotheses

2 METHOD

2.1 Participants

A power analysis was conducted using G*Power 3.1.3 (Faul, Erdfelder, Buchner, & Lang, 2009). Past research has reported medium to large effect sizes when examining associations among pain, social functioning, and quality of life within chronic pain populations (Gil et al., 2003; Greco, Freeman, & Dufton, 2007; Merlijn et al., 2003; Sawyer et al., 2004). The power analysis revealed that 61 participants would provide 90 percent power to detect a .30 effect size for a linear multiple regression for up to five tested predictors.

Participants included 76 12- to 18-year-old adolescents diagnosed with SCD who were hospitalized for SCD vaso-occlusive pain episodes at three urban children's hospitals in the southeastern United States. Adolescents or caregivers who did not speak English (n = 1), those with cognitive impairments or illness complications that would impair their ability to complete questionnaires (n = 2), and those who were in protective services or foster care custody (n = 3) were excluded.

2.2 Measures (Appendix A)

2.2.1 Demographics and medical information

Demographic data was collected using a demographic measure to assess age, gender, ethnicity, race, ethnic descent, education level, income, sickle-cell genotype, and insurance type. To assess potential diversity in ethnic descent, participants were asked to complete a family tree stating where their parents and maternal and paternal grandparents were born. These data were used to characterize the sample and included in primary analyses as necessary.

2.2.2 Pain

Adolescents were asked to rate their worst and average pain within the last four weeks on three visual analog scales (VAS's). The VAS's consisted of 100 mm lines with anchors of *no pain* and *severe pain*. The VAS is frequently utilized in pain research and has been described as a valid and reliable measure of pain in youth (Cohen et al., 2008; Varni, Walco, Wilcox, Gross, & Drabman, 1990). In the current study, a mean of the worst and average pain over the last four weeks was calculated and used as a pain composite score to characterize each participant's pain score (Huguet & Miro, 2008).

2.2.3 Social support

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) assessed perceived support from friends, family, and "special person". The SPS is a scale that uses a 7-point Likert-type format (1 = *very strongly disagree* and 7 = *very strongly agree*) and includes 12 items (e.g., "I can count on my friends when things go wrong"). Reliability and validity has been demonstrated across diverse samples, including adolescents who identify as African American (Canty-Mitchell & Zimet, 2000; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). In the current study, the total support score was used for analyses. Using Cronbach's alpha, the internal consistency for the total score in the current sample was .92.

2.2.4 Experientially similar others

Participants were asked to indicate how many of their friends also have SCD. A dichotomous variable (0 = no friends with SCD, 1 = friends with SCD) was created and used for analyses.

2.2.5 Type of communication

Adolescents were asked to indicate how many hours while hospitalized they spend participating in the following six communication categories, which were based on Pea et al. (2012): (a) text, instant message chat; (b) email or messages sent through an online social network; (c) video chat; (d) phone; (e) talking through a gaming system; (f) in-person conversations. Total hours spent utilizing each form of communication was divided by participants' length of stay to create an average usage per day for each type of communication. Forms of communication were intercorrelated so principal component analysis was conducted to determine if the variables could be reduced into principal components, or group variables, that would account for most of the variance in the observed variables. An oblique, promax rotation was employed and, utilizing a criterion of eigenvalues greater than one, two components were extracted. The two components account for 65.96 percent of the variance in the measure. Component 1 included video chatting, phone, talking through gaming system, and in-person communication and Component 2 included texting and emailing (Table 1). As such, two communication variables were derived: Live, Audio-Visual Communication (Component 1) and Modifiable, Text-Based Communication (Component 2).

In addition, a subset of adolescents ($N = 27$) responded to a qualitative open-ended question querying about relationships and communication. Specifically, they were asked, "How does being in the hospital change your relationship or communication with your friends?"

2.2.6 Stigma

An adapted Child Stigma Scale (CSS; Austin, MacLeod, Dunn, Shen, & Perkins, 2004) was used to assess the adolescents' perception of SCD-related stigma. The CSS is an 8-item Likert-type measure that was developed to assess health-related stigma in children with epilepsy.

Items are phrased to assess children's feelings of being different, how others perceive them, and disclosure. It has shown satisfactory content validity, high internal consistency reliability, and satisfactory construct validity (Austin et al., 2004; Van Brakel, 2006). For the purposes of this study, the term "epilepsy" was replaced with "SCD" (e.g., "How often do you feel people may not like you if they know you have SCD."). The total score was used in analyses. The internal consistency for this scale in the current sample was .89.

2.2.7 Quality of Life

The PedsQL SCD Module assessed quality of life. The PedsQL SCD was adapted from the previously validated PedsQL Generic Version (Varni, Seid, & Kurtin, 2001). The PedsQL SCD Module has demonstrated acceptable measurement properties (Panepinto, Torres, & Varni, 2012). The PedsQL SCD Module is a 48-item questionnaire that assesses six domains of quality of life: Pain Intensity, Pain Interference, Worry, Emotions, Disease Symptoms/Treatment, and Communication. The total quality of life score was used in analyses. Using Cronbach's alpha, the internal consistency for this scale in the current sample was .95.

2.2.8 Loneliness

The Loneliness Questionnaire-Short Version (LQ; Asher, Hymel, & Renshaw, 1984; Ebesutani et al., 2012) is a 9-item measure that assessed perceived state (i.e, in the hospital) loneliness. Participants were asked how often they feel the way described on the items (e.g., "I have no one to talk to"). The LQ-Short Version has been shown to possess good psychometric properties in child and adolescent samples (Ebesutani et al., 2012). In the current study, the total score loneliness (α = .92) were used for analyses.

2.2.9 Hospitalization health outcomes

Health outcomes during hospitalization were examined through two different assessments. To assess pain presentation in the hospital, admission and discharge pain scores were collected from the medical chart. A reduction in pain variable was calculated by subtracting discharge pain from admission pain. Reduction in pain intensity have been previously used to assess the progression of vaso-occlusive pain during hospitalization (Jacob et al., 2003; Walco & Dampier, 1990), with a higher reduction indicating an improved condition. In addition, each participant's length of stay (LOS) in the hospital was calculated by subtracting the date and time of admission from the date and time of discharge from the hospital. For analyses, LOS was converted from hours to days.

2.3 Procedure

Approval from the appropriate hospital and university institutional review boards was obtained. The study coordinator monitored the hospital schedule to determine when potential participants were admitted to the hospital. Potential participants were approached and recruited by approved research personnel 24 hours after admission, which was recommended by attending physicians, as patients would likely be heavily medicated with narcotics and physically unable to complete questionnaires immediately following admission. Recruited participants provided verbal consent or assent and participants' caregivers provided verbal consent. Following consent, participants completed the questionnaires packets in the following order: Demographics, quality of life, loneliness, support, stigma, pain, friend information, communication, and open-ended questions.

Table 1 Structure Matrix of Component Loadings

	Components		
	1	2	Communalities
Video Chat	.83		.69
Phone	.68		.57
Gaming System	.66		.48
In-person	.65		.43
Text/IM		.94	.89
Email		.93	.87

Note: KMO = .62, $p < .001$

3 DATA ANALYSES

3.1 Preliminary analyses

Descriptive statistics, including means, standard deviations, and ranges were calculated to characterize the sample (i.e., age, education, sex, ethnicity, race, country of origin, sickle-cell genotype, pain admissions, and income) and study primary variables (i.e., pain, perceived social support, similarity of peers, type of communication, perceived stigma, quality of life, loneliness, reduction in pain, and LOS). Given that the majority of participants did not know their family's income, type of insurance (i.e., state issued or private) was used to characterize the sample, which has been used as an income proxy in other pediatric hospital studies (Arnon et al., 2013; Johnson et al., 2013; Schlenz et al., 2012). To qualify for state issued insurance (i.e., Medicaid) a family must earn less than 133 percent of the federal poverty level. For example, in 2014, the income for a family of four could not exceed $23,850.00 (U.S. Department of Health and Human Services, 2014).

Data were tested for normality and statistical assumptions for correlational and regression and analyses. Normality tests revealed that the majority of the variables were positively (stigma, loneliness, LOS) or negatively (pain and social support) skewed and resistant to transformation. In order to evaluate whether the primary variables differed on any demographic variables, appropriate non-parametric correlation and mean difference analyses were conducted. Specifically, Spearman's rank correlational analyses were used to assess the associations between age and education and study variables, and mean difference tests were employed to examine differences in sex, ethnicity, race, country of origin, sickle-cell genotype, and pain admissions on primary study variables. Regression diagnostics indicated that all regression assumptions were met. Variance inflation factors (VIFs) ranged from .9 to 1.01, which indicated

no collinearity in the data. The Durbin-Watson test indicated independence of errors and normality tests confirmed normality of residuals.

3.2 Primary analyses

Correlations were conducted to determine the directions of the relations among support, friend type, communication, stigma, quality of life, loneliness, reduction in pain, and LOS. Results of the correlational analyses determined the exact predictors to be included in subsequent analyses. To test the unique predictive value of variables that were significantly associated with quality of life and loneliness, hierarchical multiple linear regression analyses were conducted. In the first hierarchical regression, covariates were entered into block 1 and appropriate variables were entered simultaneously into block 2 predicting quality of life. In the second hierarchical regression, covariates were entered into block 1 and appropriate variables were entered simultaneously into block 2 predicting loneliness. Similar hierarchical regressions were conducted for reduction in pain.

3.3 Exploratory quantitative analyses

A series of hierarchical regressions were conducted to examine hypothesized moderators (i.e., stigma, having friends with SCD, and communication) of the pain-support relation. First, a hierarchical regression was conducted with pain composite and stigma in the first block and the Stigma x Pain interaction term in the final block. Similarly, to examine the potential moderating effect of having friends with SCD on relation between pain and social support, pain and having friends with SCD were entered in the first block and the Pain x SCD Friend interaction term was entered in the final block. Finally, to examine the potential moderating effect of both types of communication (i.e., text-based and audio-visual) on the pain-support relation, two separate hierarchical regressions were conducted in which, pain and communication type were entered in the first block and the Pain x Communication interaction term was entered in the final block.

To examine the potential effect of perceived social support on the relation between pain and outcomes, hierarchical regressions were conducted with quality of life and loneliness as dependent variables. Pain composite and social support were entered in the first block, and the Pain x Support interaction term was entered in the final block. Proposed mediation analyses were not conducted to determine whether social support mediated the relation because pain was not significantly associated with social support.

3.4 Exploratory qualitative analyses

Qualitative content analysis was conducted to examine responses to the open-ended survey question. Content analysis is a commonly used to examine contextual meaning of text data through coding and identification of themes (Hsieh & Shannon, 2005; Kondracki, Wellman, & Amundson, 2002; Pope, Ziebland, & Mays, 2000). Responses to open-ended questions were transcribed. Given that minimal data exists surrounding SCD-related hospitalization in a pediatric population, following transcription, themes were identified through an inductive and inclusive process (Pasick et al., 2009). Once themes for each question were identified, responses were coded and categorized.

4 RESULTS

4.1 Preliminary and descriptive results

Sample demographic descriptive statistics including frequencies, means, and standard deviations are displayed in Table 2. Means and standard deviations of the primary study variables (i.e., pain, perceived social support, similarity of friends, inpatient and outpatient communication, perceived stigma, quality of life, loneliness, reduction in pain, and LOS) are presented in Table 3.

Non-parametric Spearman's rank correlations revealed that age and education level were highly correlated (r_s = .97, p < .001), thus, the age variable was used for subsequent analyses. Age was significantly associated with text-based communication (r_s = .32, p = .01). Age was not associated with any remaining variables (Table 4).

In terms of gender differences, Mann-Whitney U tests indicated that girls reported significantly higher loneliness (Z = .28, p = .02) and more text-based communication (Z = -2.28, p = .02). Differences between quality of life approached significance, with girls reporting lower quality of life (Z = -1.87 p = .06). No significant gender differences existed among other variables (Table 5). Kruskal Wallis tests revealed no differences among outcome variables and ethnic descent (Table 6); however there was a lack of an even distribution among categories. Similarly, mean differences tests were not run for race and ethnicity due to a lack of distribution across categories.

Given the sickle cell genotype distribution across the sample (Table 2) and that HbSS and HbS0 are considered more severe genotypes (Rees et al., 2010; Yawn et al., 2014), the sickle cell genotype variable was dichotomized into two variables: severe (n = 50) and non-severe (n = 26) SCD genotype. No significant SCD severity differences existed among variables (Table 5).

With the exception of overall quality of life, there were no significant differences in outcome in terms of insurance type. For quality of life, participants who received state issued health insurance reported significantly lower quality of life than those who had private insurance (Z = -3.11, p = .003; Table 5).

Demographic variables found to have a significant effect on primary variables were included in subsequent analyses. Specifically, those variables (i.e., gender and insurance type) found to have an effect on outcome variables were accounted for as covariates.

4.2 Primary results

Spearman rank correlations were conducted to examine the relations between the proposed predictor variables (pain, support, friend type, communication, and stigma) and relations between the proposed predictor and outcome variables (quality of life and loneliness). Analyses indicated that having friends with SCD (0 = No, 1 = Yes) was significantly positively correlated with both audiovisual and text-based communication (r_s = .29, p = .02; r_s = .25, p = .04). Having friends with SCD was not associated with total social support, but examination of subscales of the social support measure revealed that having friends with SCD was associated with (r_s = .26, p = .03) and predicted higher support from friends, F (1,69) = 6.58, p = .01, B = 3.39, SE = 1.32. Text-based communication was significantly positively correlated with audiovisual communication (r_s = .47, p < .001) and adolescents engaged in more daily text-based than audiovisual communication (Z = -3.07, p = .002). Subsequent regression analyses were conducted to determine if, controlling for age, having friends with SCD predicted text-based and audiovisual communication usage. Regression analyses revealed that having friends with SCD did not significantly predict text-based or audiovisual communication usage (B = -.19, SE = 1.53, t [69] = -.12, p = .90; B = .85, SE = .44, t [69] = 1.93, p = .06, respectively). No other significant relations among the predictor variables were found (Table 4).

4.2.1 Quality of life

Correlational analyses revealed that higher pain, higher stigma, and having friends with SCD were associated with lower quality of life (r_s = -.25, p = .03; r_s = -.49, p < .01; r_s = -.30, p = .01). Analyses revealed no other significant associations among the variables (Table 7). A hierarchical regression was conducted to examine variance in quality of life accounted for by pain, stigma and having friends with SCD. Given that quality of life differed by type of

insurance, type of insurance (state provided = 0, private = 1) was entered into Step 1, pain was entered into Step 2, and stigma and friends with SCD were entered into Step 3. Results revealed that the model including insurance type predicted quality of life, F (1,69) = 9.06, p = .004 (Table 8). The addition of pain also predicted quality of life, F (2,68) = 8.84 $p \leq .000$, accounting for an additional 9.0 percent of the variance in quality of life ($F\Delta$ = 7.72, p = .01). Similarly, the addition of stigma and having friends with SCD also predicted quality of life, F (4,66) = 12.10 $p \leq .000$, accounting for an additional 21.7 percent of the variance in quality of life ($F\Delta$ = 12.40, $p \leq .000$). Semi-partial coefficients indicated that insurance type uniquely accounted for 13.0 percent of the variance in quality of life, pain uniquely accounted for 4.4 percent, stigma uniquely accounted for 14.4 percent, and having friends with SCD uniquely accounted for 5.3 percent of the variance in quality of life.

4.2.2 Loneliness

Higher total social support and higher stigma were each associated with lower loneliness, r_s = -.31, $p < .01$; r_s = .43, $p < .01$, respectively (Table 7). To examine the unique effects of social support and stigma on loneliness, a subsequent hierarchical regression was conducted. Given that gender was associated with loneliness, gender (male = 0, female = 1) was entered into Step 1 and social support and stigma were entered into Step 2. Regression results indicated that the model including gender predicted loneliness, F (1,71) = 4.27, p = .04. The model containing social support and stigma also predicted loneliness, F (3,69) = 8.53, $p < .000$, accounting for an additional 21 percent of the variance in loneliness ($F\Delta$ = 9.96, $p < .000$; Table 9). In the second model, both social support and stigma predicted loneliness in expected directions. Examination of partial coefficients indicated that gender, social support, and stigma accounted uniquely for 6.8 percent (p = .01), 12.8 percent (p = .001), and 6.1 percent (p = .02) of the variance in

loneliness, respectively. Moderation analyses were conducted to determine if gender moderated the relations between social support and loneliness and stigma and loneliness. Gender did not significantly moderate the relation between social support and loneliness, B = -.15, SE = .13, p = .25, or the relation between stigma and loneliness, B = -.09, SE = .20, p = .66.

Lower quality of life was also significantly associated with higher loneliness in the hospital (Table 7); however, when entered into the regression model with social support and stigma, it did not uniquely predict loneliness, B = .08, t (72) = -1.46, p = .15.

4.2.3 Hospital outcomes

Higher stigma and higher loneliness was associated with less reduction in pain during hospitalization (r_s = -.35, p = .002; r_s = .-23, p = .046, respectively). Having friends with SCD and higher quality of life was associated with more reduction in pain (r_s = .25, p = .04; r_s = .26, p = .03, respectively). A hierarchical regression was conducted to examine the unique effects of having friends with SCD, stigma, quality of life, and loneliness on reduction in pain. To control for pain in the last month and given that pain was associated with quality of life, pain composite was entered into the first step and stigma, quality of life, and loneliness were entered into the second step. Regression results indicated that the second model predicted less reduction in pain, F (5,66) = 2.93, p = .02, and accounted for more variance ($F\Delta$ = 3.36, p = .02). Within the second model, stigma was the only variable that uniquely predicted less reduction in pain (B = -.11, SE = .03, p = .04) (Table 10). LOS was not associated with any other variables (Table 4).

4.3 Exploratory Quantitative Results:

4.3.1 Pain X Stigma interaction

Regression analyses revealed that the second model containing the Stigma X Pain interaction accounted for more variance in social support, ΔF (3,70) = 5.22, p = .03, and the

interaction term predicted higher social support, $B = .21$, $p = .03$ (Table 11). Moderation probing to examine the simple slopes at one standard deviation below and above the mean of stigma revealed that higher pain predicted higher social support at high levels of stigma, $B = 3.94$, $SE = 1.29$, $p = .003$, but not at low levels of stigma, $B = .36$, $SE = .89$, $p = .69$ (Figure 4).

4.3.2 Pain X Friends with SCD interaction

Given that having friends with SCD significantly predicted support from friends, the total friend support subscale was used for these analyses. Regression analyses revealed that the Pain X Friend type interaction term did not predict social support from friends, $B = -.41$, $p = .53$, and did not account for more variance, ΔF (3,70) = .41, $p = .53$ (Table 12).

4.3.3 Pain X Communication interactions

Regression analyses revealed that, controlling for age and gender, the pain X text-based communication interaction term did not predict social support, $B = -.20$, $p = .09$, and did not account for more variance, $\Delta R^2 = .04$, ΔF (5,62) = 3.00, $p = .09$ (Table 13). Similarly, the support X audiovisual communication interaction term did not predict support, $B = .07$, $p = .71$, and did not add more variance, $\Delta R^2 = .002$, ΔF (3,68) = .14, $p = .71$ (Table 14). Overall study results are displayed in Figure 5.

4.3.4 Support Moderation for Quality of Life and Loneliness

Regression analyses revealed that, after controlling for insurance, the Pain X Support interaction term did not predict quality of life, $B = -.11$, $p = .16$, and did not account for more variance, $\Delta R^2 = .02$, ΔF (4,67) = 3.15, $p = .16$. Similarly, controlling for gender, the Pain X Support interaction term did not predict loneliness, $B = -.02$, $p = .31$, and did not add more variance, $\Delta R^2 = .01$, ΔF (4,69) = 2.09, $p = .31$. Overall significant study results are displayed in Figure 5.

4.4 Qualitative results:

Qualitative content analysis revealed four main themes in the responses to "How does being in the hospital change your relationship or interactions with your friends." The themes for each question are described in more detail below.

How does being in the hospital change your relationship or interactions with your friends?

No change (n = 12). Adolescents indicated that being in the hospital did not influence their relationships or interactions with their friends. One adolescent cited that the use of social media contributes to the maintenance of relationships/interactions.

Improves social connection (n = 6). Adolescents reported that while in the hospital, their interactions increase and their friends tended to reach out to them more frequently. Adolescents expressed that their friends' increased concerns resulted in them feeling closer to and more appreciative of their friends.

Impairs social engagement (n = 8). Adolescents indicated that being in the hospital decreases their opportunity to interact with their friends, which resulted in them losing connections with their friends. Adolescents also reported increased fatigue and irritation while in the hospital, which resulted in avoidance of friends.

Increases negative interactions (n = 1). An adolescent reported receiving negative treatment from friends, indicating that friends tend to treat them like a "baby."

Table 2 Participant Demographic Data

Variable	*M* (*SD*)
Age	14.97 (2.01)
Education	9.55 (1.95)
	N (%)
Gender	
Male	34 (44.7)
Female	42 (55.3)
Ethnicity	
Hispanic/Latino	3 (3.9)
Not Hispanic/Latino	38 (50)
Race	
American Indian/Alaskan	1 (1.3)
Black or African American	72 (94.7)
Multi-racial	3 (3.9)
Missing	1 (1.7)
Ethnic Descent	
Africa	6 (7.9)
Caribbean Islands	6 (7.9)
Central America	1 (1.3)
North America	43 (56.6)
South America	1 (1.3)
Caribbean and Africa	2 (2.6)
Missing	13 (17.1)
Sickle Cell Genotype	
HbSS	45 (60.0)
HbSC	21 (28.0)
SB^{+}Thal	5 (6.6)
SB^{0}Thal	4 (5.3)
Insurance	
State	52 (68.4)
Private	21 (27.6)
Missing	3 (3.9)

Table 3 Primary Outcomes Descriptive Data

Variable	*N* (%)
Friends with SCD	
Yes	34 (44.7)
No	39 (51.3)
Missing	3 (3.9)
	M (*SD*)
Pain (0-10)	
Average Pain	5.02 (2.61)
Worst Pain	8.13 (2.57)
Pain Composite	6.61 (2.18)
Social Support (12-84)	
Friend Support	21.44 (5.79)
Total Support	68.77 (12.49)
Friend Communication (Hours per Day)	
Email	.83 (1.40)
Text	1.26 (1.66)
Phone	.49 (.73)
Video Chat	.15 (.35)
Gaming Chat	.04 (.15)
In-person	.25 (.54)
Total Audiovisual Communication	1.08 (1.89)
Total Text-Based Communication	2.58 (6.19)
Stigma (8-40)	
Total	19.47 (8.59)
Quality of Life (0-100)	
Total	48.40 (17.69)
Loneliness (9-45)	
Total	13.80 (6.84)
Hospital Outcomes	
Change in Pain (Admission – Discharge; 0-10)	5.14 (3.26)
Length of Stay (Days)	5.05 (3.19)

Table 4 Intercorrelations among Age and Primary Variables

Variable	1	2	3	4	5	6	7	8	9	10
1. Age	1.00									
2. Pain	.10	1.00								
3. Social Support	.16	.14	1.00							
4. SCD Friends	.09	.09	.21	1.00						
5. Text-Based Communication	.32**	.09	-.10	.29*	1.00					
6. Audiovisual Communication	.34**	.01	.08	.25*	.47**	1.00				
7. Stigma	.02	.03	.00	.15	.19	-.05	1.00			
8. Quality of Life	.09	-.24*	-.21	-.23*	-.02	-.11	-.49**	1.00		
9. Loneliness	.08	-.03	-.34**	.16	.22	.08	.45**	-.29*	1.00	
10. Change in Pain	.14	-.05	-.02	-.25*	-.14	-.08	-.35**	.26*	-.23*	1.00
11. Length of Stay	.08	.15	.18	.18	-.11	.07	-.02	-.18	-.08	.03

Notes. * $p < .05$; ** $p < .001$.

Table 5 Mean Differences among Variables

	Gender		SCD Genotype		Insurance	
Variable	Girls (M ± SD)	Boys (M ± SD)	Severe (M ± SD)	Non-Severe (M ± SD)	State Issued (M ± SD)	Private (M ± SD)
Pain Composite	6.98±1.93	6.13±2.14	6.53±2.16	6.76±2.26	6.60±2.36	6.99±1.30
Social Support	69.65±11.45	65.33±17.05	67.86±3.94	67.47±15.00	68.55±12.79	69.40±11.50
SCD Friends	2.34±3.98	1.21±2.73	2.16±3.94	1.33±2.60	1.82±3.66	2.15±3.48
Text-Based Comm	3.67±1.96*	1.26±1.96*	2.71±4.35	3.70±3.85	2.99±4.34	3.21±4.07
Audiovisual Comm	1.30±2.24	.80±1.38	.25±.72	.43±85	.31±.73	.35v.90
Stigma	20.02±9.54	18.82±7.45	19.27±8.76	19.92±8.58	19.77±8.82	18.71±8.72
Quality of Life	44.17±7.87	53.33±18.99	50.24±19.97	44.48±11.96	44.14±17.34**	57.08±14.94**
Loneliness	17.00±7.87*	13.51±5.99*	14.84±6.52	16.59±8.52	15.38±7.11	15.78±8.03
Change in Pain	4.79±3.44	5.63±2.99	5.41±3.14	3.14±3.49	4.87±3.50	5.67±2.52
Length of Stay	5.00±3.43	5.21±2.91	5.54±3.61	4.24±1.95	5.09±3.26	5.09±3.11

Notes. *$p < .05$; **$p \leq .01$

Table 6 Ethnic Descent Group Differences

	Chi-Square	*p* value
Pain	8.10	.23
Total Social Support	3.225	.78
Friends with SCD	1.81	.94
Inpatient Media Usage	6.08	.42
Inpatient In-Person Usage	8.13	.23
Stigma	4.04	.67
Quality of Life	4.43	.62
Loneliness	6.41	.38
Change in Pain	3.87	.70
Length of Stay	6.82	.34

Table 7 Intercorrelations among Primary Variables

Variable	1	2	3	4	5	6	7
1. Pain	1.00						
2. Social Support	.14	1.00					
3. SCD Friends	.11	.21	1.00				
4. Text-Based Communication	.09	-.10	.28*	1.00			
5. Audiovisual Communication	.01	.08	.32*	.47**	1.00		
6. Stigma	.03	.00	.15	.03	.00	1.00	
7. Loneliness	-.03	-.34**	.16	.22	.08	.45**	1.00
8. Quality of Life	-.24*	-.21	-.23*	-.02	-.11	-.49**	-.24*

Notes. * $p < .05$; ** $p < .01$.

Table 8 Hierarchical Regression Analyses of Pain, Friends with SCD, and Stigma as Predictors of Quality of Life

Step	*R*	R^2	*B*	SE	*t*	*F*Δ	ΔR^2
Block 1	.34	.12					
Insurance			12.88	4.28	3.01**		
Block 2	.46	.22**				8.15	.097
Insurance			13.88	4.10	3.39**		
Pain			-2.46	.88	-2.78**		
Block 3	.71	.50**				17.96	.28
Insurance			13.61	3.56	3.81**		
Pain			-1.77	.78	-2.28*		
SCD Friends			-8.24	3.29	-4.03**		
Stigma			-.79	.19	-4.03**		

Notes. * $p < .05$; ** $p < .01$.

Table 9 Hierarchical Regression Analyses of Gender, Social Support, and Stigma as Predictors of Loneliness

Step	*R*	R^2	*B*	SE	*t*	*F*Δ	ΔR^2
Block 1	.24	.06					
Gender			3.71	1.80	2.07*		
Block 2	.52	.27**				9.96	.21**
Gender			4.11	1.60	2.56**		
Social Support			-.14	.06	-2.42**		
Stigma			.33	.10	3.50**		

Note. * $p < .05$; ** $p < .01$.

Table 10 Hierarchical Regression Analyses of Pain, Stigma, Quality of Life, and Loneliness as Predictors of Reduction in Pain

Step	*R*	R^2	*B*	SE	*t*	*F*Δ	ΔR^2
Block 1	.12	.02					
Pain			-.18	.18	-1.04		
Block 2	.43	.18*				3.36	.17*
Pain			-.08	.18	-.43		
Friends with SCD			-1.11	.76	-1.47		
Stigma			-.11	.05	-2.07*		
Quality of Life			.02	.03	.60		
Loneliness			.02	.05	-.43		

Notes. * $p < .05$.

Table 11 Pain x Stigma Interaction and Social Support

Step	*R*	R^2	*B*	SE	*t*	*F*Δ	ΔR^2
Block 1	.25	.06					
Pain			1.53	.75	2.03*		
Stigma			-.21	.20	-1.04		
Block 2	.36	.13				5.22*	.07
Pain			2.20	.79	2.79*		
Stigma			-.32	.20	-1.59		
Pain*Stigma			.21	.09	2.28*		

Notes. * $p < .05$.

Table 12 Pain x Friends with SCD Interaction and Friend Social Support

Step	*R*	R^2	*B*	SE	*t*	*F*Δ	ΔR^2
Block 1	.34	.12					
Pain			.47	.31	1.53		
Friends with SCD			3.16	1.32	2.40*		
Block 2	.35	.12				.41	.01
Pain			.62	.38	1.61		
Friends with SCD			3.22	1.33	2.42*		
Pain*Friends with SCD			-.41	.64	-.64		

Notes. * $p < .05$.

Table 13 Pain x Text-Based Communication Interaction and Social Support

Step	*R*	R^2	*B*	SE	*t*	*F*Δ	ΔR^2
Block 1	.21	.04					
Pain			1.32	.76	1.73		
Text-Based Communication			.01	.27	.05		
Block 2	.22	.04				.29	.004
Pain			1.43	.79	1.80		
Text-Based Communication			-.09	.34	-.27		
Pain*Text-Based Communication			.15	.27	.53		

Table 14 Pain x Audiovisual Communication Interaction and Social Support

Step	*R*	R^2	*B*	SE	*t*	*F*Δ	ΔR^2
Block 1	.25	.06					
Pain			1.24	.76	1.63		
Audiovisual Communication			1.01	.89	1.13		
Block 2	.25	.06				.09	.001
Pain			1.26	.77	1.63		
Text-Based Communication			1.18	1.07	1.11		
Pain*Audiovisual Communication			-.13	.43	-.30		

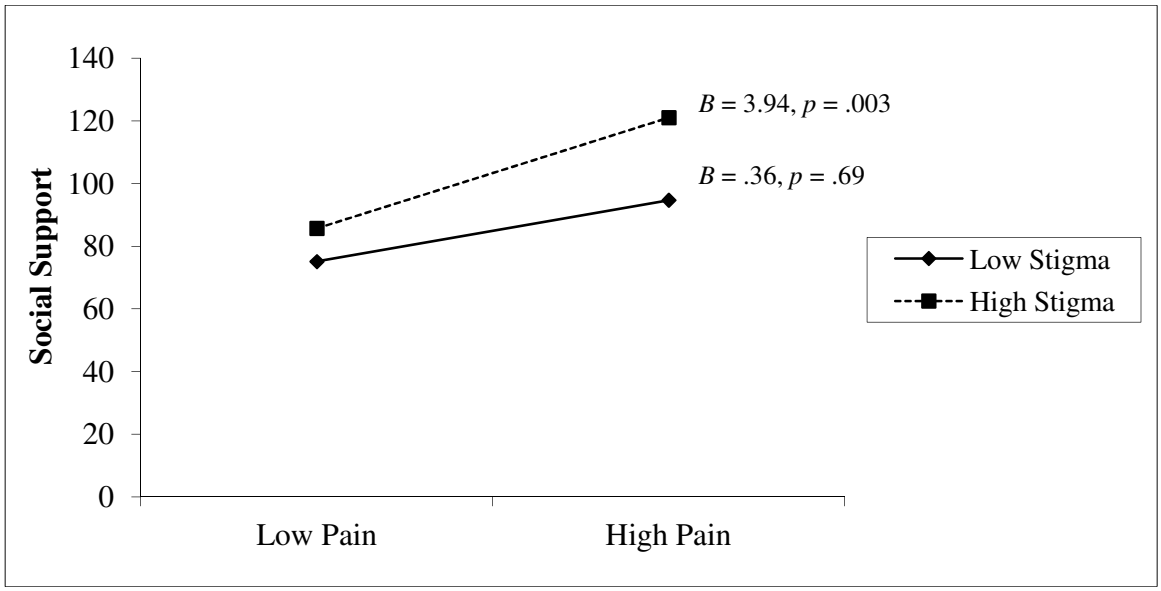
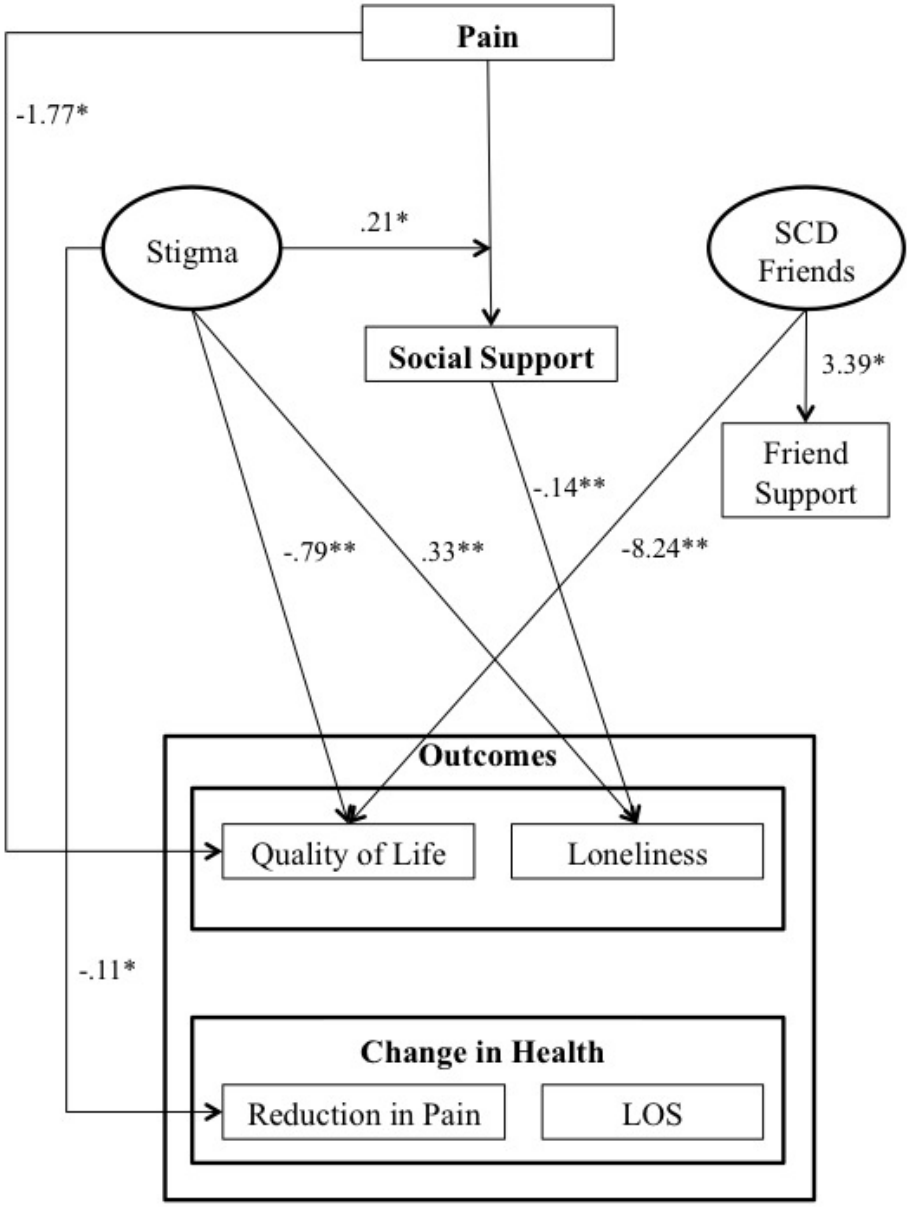


Figure 4. Pain x Stigma Interaction



Note. Numbers represent regression coefficients (*B*). Only significant paths are displayed; **p* < .05; ***p* < .01

Figure 5. Summary of Regression Results

5 DISCUSSION

Annually, there are approximately 100,000 individuals in the United States living with SCD and 1000 children born with SCD (Koury, 2011). Despite improvements in the treatment of SCD over the last few decades, individuals with SCD continue to be at risk for a myriad of negative psychosocial outcomes. Pain is the primary symptom of SCD and recurrent and unpredictable vaso-occlusive episodes are often the most debilitating complication of SCD. Children with more severe types of SCD are hospitalized, on average, two to three times annually. In the general pediatric pain literature, it is well documented that pain affects psychological, physical, and social functioning as well as overall quality of life. Youth with SCD are no exception and experience decreased quality of life and social impairment as a result or recurrent pain and hospitalizations (Dampier 2010; Edwards 2005; Schlenz 2012). Compounding the issues, youth with SCD may experience added stress and social isolation as a result of SCD-related stigmatization from peers, community members, or healthcare providers (Jenerette & Brewer, 2010).

In other illness populations, social support has served as a protective factor against negative outcomes. Researchers have proposed social support models within the context of chronic illness highlighting the examination of the social environment, similar peers, and the effect of social support on psychosocial outcomes (Dennis, 2003; Frohlich, 2014; Thoits, 2011); however, there is a paucity of research examining aspects of social support in relation to psychosocial outcomes in the broader pediatric pain literature as well as within the pediatric sickle cell population.

In an attempt to address this gap in the pediatric pain and SCD literature and test aspects of Frohlich's (2014) social support model for people with chronic health conditions in the

pediatric SCD population, the primary aims of the current study were to conduct a fine grained analysis of social support and (a) examine associations of pain, perceived social support, having similar friends, type of friend communication, and perceived stigma and (b) how these factors influence quality of life and loneliness in adolescents hospitalized for sickle cell pain. A secondary aim was to examine the associations among psychosocial outcomes (i.e., quality of life and loneliness) and health outcomes while in the hospital (i.e., reduction in pain and length of hospital stay). Exploratory aims included (a) determining if stigma, having friends with SCD, and communication moderated the pain-support relation, (b) whether social support mediates and/or moderates the relation between pain and quality of life and loneliness and the association among psychosocial outcomes (i.e., quality of life and loneliness), and (c) a qualitative assessment of adolescents' perception of how hospitalization influences their friendships.

5.1 Descriptives and Demographics

The comparability of average scores on measures in the current sample to other pediatric studies varied. Pain intensity scores were similar to SCD inpatient data (Franck, Treadwell, Jacob, & Vichinsky, 2002) but higher than other outpatient studies that captured pain ratings over a period of time (Jacob, Duran, Stinson, Lewis, & Zeltzer, 2013; McClish et al., 2009; Wilkie et al., 2010). Although adolescents reported similar levels of social support as other African American youth samples (Brown, 2008; Canty-Mitchell & Zimet, 2000), they reported higher levels of support than other chronic illness youth samples (Ingerski, Janicke, & Silverstein, 2007; Kim et al., 2014). Mean rates of communication in the current sample were, overall, lower than other large-scale studies (Lepp, Barkley, & Karpinski, 2014; Pea et al., 2012; Rosen, Carrier, & Cheever, 2013). However, most studies examine either overall cell phone usage or separate forms of communication (e.g., texting, Facebook), thus, it is unclear how the

current data on live, audiovisual versus modifiable, text-based communication compares to broader pediatric populations. In terms of stigma, adolescents in the current sample reported higher average levels of stigma than pediatric patients with epilepsy (Jacoby, 2008; Rood, Schultz, Rausch, & Modi, 2014; Ryu, Lee, Eom, & Kim, 2015) and moderate to severe mental health conditions (Moses, 2009, 2010, 2015). Past research has suggested that the public's limited knowledge of SCD and SCD-related symptoms paired with the potential for racial discrimination, stereotyping, and mistrust in the healthcare environment may place individuals with SCD at a heightened risk for feeling stigmatized (Jenerette et al., 2014; Jenerette & Brewer, 2010; Todd, Green, Bonham, Haywood, & Ivy, 2006). In addition, SCD-related adolescent developmental delays (e.g., small body mass, delayed secondary sex characteristics, delayed menarche) may result in youth with SCD feeling different and more stigmatized by peers, which may be particularly problematic during adolescence when teens strive to be similar to their peers (Patel & Pathan, 2005; Singhal, Thomas, Cook, Wierenga, & Serjeant, 1994).

Adolescents in the current study reported less loneliness than both healthy adolescents (Alderfer et al., 2015; Chen et al., 2004) and adolescents with chronic pain (Forgeron, Chorney, Carlson, Dick, & Plante, 2015), which was unexpected given that hospitalization is often associated with increased feelings of loneliness (Asnani et al., 2010; Lambert et al., 2013). Examination of the qualitative data indicated that adolescents might have mixed feelings about how being in the hospital affects their friendships, which may help explain the levels of loneliness in the adolescents sampled in this study. In contrast, the current sample reported marked lower quality of life than outpatient and inpatient pediatric SCD samples (Bhatia et al., 2015; Panepinto, Pajewski, Foerster, Sabnis, & Hoffmann, 2009). Regarding hospital outcomes, when compared to other pediatric SCD samples, adolescents in the current sample had longer

hospital admissions and had smaller declines in pain throughout their hospital stay (Panepinto, Brousseau, Hillery, & Scott, 2005; Sobota et al., 2012).

Consistent with other North American pediatric SCD studies, almost all of the adolescents identified as Non-Latino, Black or African American and approximately half of the sample reported origins from North America, with the remaining sample reporting origins from a variety of other regions including Africa, Caribbean Islands, and Central and South America. Given the little diversity represented in the current study, potential influences of factors related of race and/or ethnic origin could not be appropriately examined. The majority of adolescents had state insurance indicating that most of the current sample was living at or below the poverty line, which uniquely predicted lower quality of life. Other studies conducted with children and adolescents with SCD (Panepinto, Pajewski, Foerster, Sabnis, & Hoffmann, 2009) as well as other chronic illnesses (Erickson et al., 2002; Naughton, Ruggiero, Lawrence et al, 2008; Van Dellen et al., 2007; Varni, Burwinkle, Seid, & Skarr, 2003) have reported similar findings suggesting that lower socioeconomic status and/or government-funded insurance has a negative impact on health-related quality of life as these families may have limited access to resources (e.g., transportation to medical appointments, ability to miss work, childcare for other children in the home) to help manage the illness and associated stressors.

Within the current sample a majority of adolescents had more severe forms of SCD; however, sickle cell genotype was not associated with other variables including pain, quality of life, and length of hospital stay. Given that this was an inpatient sample, these adolescents may not be representative of a broader pediatric SCD population with varying degrees of complications. Of note, significant variability often exists among sickle cell genotypes and other studies have reported mixed findings in regard to disease severity predicting psychosocial

outcomes (Lamia, Smith-Whitley, & Ohene-Frempong, 2002; Burlew et al., 2000; Casey, Brown, & Bakeman, 2000; Lutz, Barakat, Smith-Whitley, & Ohene-Frempong, 2004), which has lead researchers to suggest that patient perception of severity or measures of adaptation or health-related quality of life may be more accurate indicators (Barakat, Lash, Lutz, Nicolaou, & Brown, 2006).

In terms of gender, adolescent girls reported higher levels of loneliness and more text-based communication. There was a trend for girls to report lower quality of life as well. Although gender was not a significant moderator, it did uniquely predict increased loneliness. Current results suggest that girls may be as risk for negative outcomes, which is consistent with a previous study assessing quality of life in youth with SCD (Dampier et al., 2010), but adds to the existing inconsistent findings on gender differences in the loneliness literature. In a meta-analysis of loneliness in healthy youth, Mahon et al. (2006) found that the majority of studies reported no gender differences, but those that did reported that boys had higher levels of loneliness. Reported social support, however, did not differ by gender, which adds to the inconsistent literature in this area. Researchers have argued that measurement of support is biased in a feminine manner when measures assess emotional expressivity and intimacy. Although, the measure used in the current study includes a few items that assess emotional expression, other items assess instrumental assistance and dependability which may tap into factors that are more important for boys (Bagwell & Schmidt, 2013; Brendgen et al., 2001). However, other studies utilizing this measure with healthy populations have found gender differences with girls reporting higher support than boys (Bruwer, Emsley, Kidd, Lochner, & Seedat, 2008; Canty-Mitchell & Zimet, 2000; Osman, Lamis, Freedenthal, Gutierrez, & McNaughton-Cassill, 2014). Thus, the current findings may coincide with inconsistencies in the

literature and/or may be representative of the current sample and suggest that complications related to SCD (e.g., pain and hospitalizations) may have similar effects on social support for boys and girls.

Gender and age were associated with the use of text-based communication such that being a girl and older were associated with more communication. Texting and other forms of electronic media communication have been deemed an increasingly popular teen "phenomenon" and defining feature of adolescent culture (Lenhart et al., 2010; Ling, Bertel, & Sundsøy, 2012; Pea et al., 2012; Rideout et al., 2010; Tynes & Mitchell, 2013; Yang & Brown, 2013). Research findings are consistent with the current study findings in that text messaging tends to increase with age (Tynes & Mitchell, 2013), and although boys' and girls' use has increased, girls engage in this form of communication more frequently (Lenhart et al., 2010; Ling et al., 2012).

5.2 Social Support

Primary analyses revealed that, contrary to hypotheses, perceived social support was not associated with pain, stigma, having friends with SCD, or communication usage. These results are inconsistent with past pediatric pain literature that have found poor social functioning in adolescents with pain conditions; however, studies to date have only examined social likeability and social functioning (e.g., going out or seeing friends) without assessing perceived social support in these teens (Forgeron et al., 2010; Fuggle et al., 1996; Noll et al., 2010, 2007; Palermo et al., 2002). That being said, given the social support literature linking poor health status to isolation and weaker friendships (Haas et al., 2010), and models suggesting that social support may mediate and moderate the relation between pain and outcomes (Dennis, 2003; Frohlich, 2014), it was expected that reported pain would influence perception of support and that the stress-buffering hypothesis would be supported. Both social support and pain variable data were

substantially negatively skewed in the current study, which may have limited the ability to detect significant relations. Further, the current study did not include a comparison group so it is not clear whether or not adolescents reported lower support than healthy peers, which would coincide with some of the past research on social functioning and pain.

Examination of relations within proposed factors of social support did allow for further exploration of social support in the current sample. Specifically, stigma moderated the effect of pain on social support; however, contrary to hypotheses, at high levels of stigma, higher pain predicted more perceived support. This finding was surprising given that past literature examining stigma in SCD and other chronic illnesses has highlighted the harmful effects of stigma (Burnes et al., 2008; Jenerette & Brewer, 2010; Weiss et al., 2006). Considering that the current results revealed that stigma alone was not associated with social support, one potential explanation may be that adolescents feel supported and may also feel stigmatized by others who may not be members of their support network, but those who experience more stigmatization may seek out more support when experiencing more pain. Thus, the added stress results in seeking out more support, which then results in them feeling more supported.

Approximately half of the sample had a friend that also had SCD, and having a friend with SCD was associated with increased audiovisual and text-based communication. To date, this was the first study to examine the effects of having experientially similar others in an adolescent SCD population. Neither having friends with SCD nor friend communication were associated with perceived overall support, but having friends with SCD was related to increased perceived support from friends in particular. Social support researchers have proposed that individuals may receive more specialized support from experientially similar others (Thoits, 2011). Although having friends with SCD was not associated with overall support, its relation to

support from friends is consistent with Thoits' (2011) theory and suggests that adolescents with SCD may receive more specialized support if they have friends who also have SCD. Though it was not assessed directly, results also suggest that adolescents who have friends who also have SCD may feel more comfortable communicating with their friends while in the hospital.

Form of communication was not associated with social support or other outcomes. Similarly, qualitative themes revealed that communication with friends while in the hospital is perceived as sometimes positive and sometimes negative. Past research on electronic media has produced some conflicting results on the consequences of face-to-face vs. electronic forms of communication. To my knowledge, the current study was the first to identify and examine text-based and audiovisual components of communication, although other researchers examining individual forms of communication has coincided with the media richness (Daft & Lengel, 1986) and social presence (Short, Williams, & Christie, 1976) theories, which propose that richer communication or communication that involves more visual cues and expression of emotion and affection results in more effective communication. Sherman, Michikyan, and Greenfield (2013) found that in-person communication and video chat were associated with comparable levels of bonding and greater bonding than instant messaging. The current study did not produce results consistent with these findings; however, data were collected in a unique environment and may suggest that neither text-based nor audiovisual forms of communication in the hospital influence perceived social support.

5.3 Quality of Life and Loneliness

In line with Frohlich's (2014) model, primary aims also sought to examine how social support and other variables influenced quality of life and loneliness. Overall pain, perceived stigma, having friends with SCD, and insurance type all proved to be important factors in

predicting quality of life; however, not all variables predicted quality of life in expected directions. Consistent with other pediatric pain studies (Dampier et al., 2010; Huguet & Miro, 2008; Sawyer et al., 2004), higher pain predicted lower quality of life. Similarly, more perceived stigma predicted lower quality of life, which is similar to other data reported in the adult literature (Jenerette & Brewer, 2010; Jenerette et al., 2005). Further, as also seen in other pediatric SCD populations (Panepinto et al., 2009), lower socioeconomic status, or government-funded insurance, predicted lower health-related quality of life. Interestingly, although having friends with SCD predicted higher levels of support, having friends with SCD predicted lower quality of life. One potential explanation for these conflicting results is that although having friends who share similar experiences may predict more perceived support, it may also result in more exposure to potential negative disease complications. For example, if a friend is experiencing significant pain and/or is repeatedly admitted to the hospital, it may exacerbate worries about one's own illness. Another potential explanation may be that friends with SCD may be supportive but may not be modeling appropriate coping or healthy behaviors. It has been proposed that social support can influence individual coping resources and can expose individuals to new information (McAlister, Perry, & Parcel, 2008), which can have positive or negative effects depending on the information received and the interpretation of this information (Thoits, 1995). Forgeron et al. (2015) recently conducted a study examining communication and friendship among adolescent girls who had chronic pain and found that conversations among adolescents often involved talking about one's pain and the authors discussed the potential negative effects of co-rumination among these adolescents. Thus, the adolescents in the current study may experience an added level of support from their similar friends, but may also be

exposed to poor coping models, disease experiences, or information which could have potentially influenced their appraisal or feelings about their own experiences and health.

Examination of feelings of loneliness while in the hospital revealed that as hypothesized, increased social support predicted decreased feelings of loneliness in the hospital whereas increased perceived stigma predicted increased feelings of loneliness. Themes that emerged from the qualitative assessment coincided with these quantitative findings and indicated that those adolescents that had friends that communicated with them and/or reached out to them to offer support felt no different in the hospital or even improved social connection. Thus, friends' actions and reactions seem to be an important factor. Girls reported higher levels of loneliness, but gender did not influence the relations between support-loneliness and stigma-loneliness relations, with all three factors predicting a fourth of the variance in loneliness. These findings coincide with other literature examining effects of gender and social support on loneliness (Mahon, Yarcheski, Yarcheski, Cannella, & Hanks, 2006).

Stigma was a significant predictor of increased loneliness and decreased quality of life, which is consistent with other adult SCD studies that indicate that perceived stigma is associated with a host of negative outcomes (Burnes et al., 2008; Jenerette et al., 2014, 2005; Jenerette & Brewer, 2010). The measure used to assess stigma in the current study focused on stigma from peers and given that adolescents are highly peer-focused, experiencing stigmatization from peers may be particularly problematic in youth with SCD. As discussed above, youth may also be at a heightened risk of stigmatization as a result of racial discrimination and stereotyping (Jenerette et al., 2014; Jenerette & Brewer, 2010; Todd et al., 2006), which may contribute to their overall perception of stigma and thus negatively influence outcomes.

5.4 Hospital Outcomes

Secondary aims sought to examine another aspect of Frohlich's model and determine if quality of life and loneliness predicted health outcomes (i.e., reduction in pain and length of stay). High quality of life and low loneliness were associated with greater reduction in pain in the hospital. Inconsistent with hypotheses, quality of life and loneliness were not associated with length of stay. Although stigma was not included in the secondary aims, perceived stigma was the only variable measured that uniquely predicted changes in pain, with more stigma predicting less reduction in pain while in the hospital. Past studies have concluded that SCD-related stigma is associated with negative outcomes, including depression, poor disease management, and delayed initiation of medical care (Jenerette et al., 2014, 2005; Jenerette & Brewer, 2010), which may help explain the current findings. Specifically, SCD-related stigma may influence adolescents' overall ability to manage and cope with their illness, which is particularly important during hospitalization and may impair their ability to engage in treatment recommendations to help reduce their pain.

To my knowledge, this is the first study to examine the effects of psychosocial outcomes on medical data in a hospitalized pediatric SCD or chronic pain sample. Examination of factors related to hospital outcomes have been conducted in other populations and these studies have primarily cited factors related to clinical practice, medication management, and organization of care as primary factors in hospital outcomes, though some social factors (i.e., communication with health care providers) and psychological factors (i.e., anxiety and depression) have been proposed as contributing factors of hospital outcomes as well (Gruenberg et al., 2006; Jacob et al., 2003; Xiao, Douglas, Lee, & Vemuri, 1997). Thus, the current findings stress the importance of considering and assessing psychosocial factors, including stigma, as these factors may have implications for health status in the hospital.

5.5 Limitations

The current study adds to literature assessing psychosocial factors and pain and provides a more extant examination of social support and its relation to outcomes in a pediatric SCD population; however, the study is not without limitations. In regards to the study sample, the adolescents enrolled in this study reported lower quality life, had less reduction in pain scores while hospitalized, and were in the hospital longer than other pediatric SCD samples in the literature, which suggests that the current sample may represent a more severe population and may not generalize to broader SCD populations. The distributions of some of the study variables may have also influenced the results thus limiting generalizability to other populations. Specifically, pain and social support were considerably negatively skewed. Further, loneliness was positively skewed and adolescents in the current sample reported lower levels of loneliness compared to other samples.

In terms of study design, the present study was a cross-sectional study and did not include a comparison group, which is associated with limitations. Specifically, although some measures asked participants to report on either past or present feelings or behaviors, measured were collected at the same time so causality cannot be inferred from the current results. In addition, directionality of the results cannot be confirmed. For example, it is plausible that hypothesized outcome variables, such as quality of life or loneliness, might instead predict friendships in adolescents with SCD. Similarly, there might be other variables influencing the relations among study constructs. The absence of a comparison group also limits the capability to conclude how the adolescents in the present study compare to other chronic illness and healthy populations. Due to inability to record and track real-time communication with friends, communication data collection was self-reported, which may have limited accuracy. Other electronic media studies have reported that heavy users tend to underestimate their use whereas light users tend to

overestimate usage (Abeele, Beullens, & Roe, 2013). Further, although patients were recruited 24-hours post-admission to avoid medication confounds, patients are medicated throughout their hospitalization and side effects from analgesic medication (e.g., fatigue) may have interfered with their ability to communicate with friends throughout the day. Although an aim of the study was to assess perceived social support, social functioning or content of communication were not assessed, which may have provided a more detailed picture of adolescents' participation in social activities and how functioning may relate to perceived social support as well as other outcomes. Future studies should examine both perceived support and functioning. Measurement of medical and hospital outcomes was also limited to pain and LOS data, which represent a subset of medical outcomes that may be important factors in the management and severity of SCD. Thus, further assessment of other medical factors (medication, clinical practice, treatment policies, etc.) and relations among these factors and psychosocial outcomes is warranted. Lastly, adolescents in the present study completed measures while in the hospital for pain, which may have influenced their perception of pain and other outcomes.

6 CONCLUSIONS AND CLINICAL IMPLICATIONS

The current study aimed to explore factors of social support and relations among psychosocial and medical outcomes and test aspects of Frohlich's (2014) social support model in adolescents hospitalized for SCD pain episodes. Overall, results presented an expanded picture of aspects of social support within this population and provided mixed support for Frohlich's model. Perceived social support predicted decreased loneliness in the hospital but did not mediate or moderate the relation between pain and loneliness or pain and quality of life. Pain was not associated with social support; however, at high levels of stigma, more pain predicted increased support. Having friends with SCD was associated with increased communication with

friends and predicted increased perceived support from friends but also predicted lower quality of life, which may be the result of exposure to modeling of poor coping behavior. Stigma emerged as a unique predictor of lower quality of life, higher loneliness, and less reduction in pain during hospitalization. Further, girls and adolescents receiving government-funded insurance may also be at risk for negative outcomes. Qualitative assessments revealed that hospitalization may have varying effects on adolescents' friendships and these effects may depend how friends in their support environment respond to their hospitalization. Given these findings, adolescents with SCD may benefit from peer mentoring programs, which have been studied in other populations and include trained mentors who provide appropriate education and modeling as well as appropriate support surrounding pain and hospitalizations (Allen, Tsao, Hayes, & Zeltzer, 2011; Maslow et al., 2013; Stewart, Barnfather, Magill-Evans, Ray, & Letourneau, 2011). Peer mentoring programs may also help adolescents learn how to cope with SCD-related symptoms and the effects of stigma as well as provide socially-based education surrounding effective ways to seek support from friends and address feelings of peer stigmatization.

The current study also examined different forms of communication in adolescents with SCD and unique components of text-based and audiovisual communication emerged. Although neither form of communication predicted support or other outcomes, forms of text-based and audiovisual communication are becoming increasingly popular among adolescents and the current results may indicate that, given the generational changes in adolescent communication, the differences between text-based and live, audiovisual forms of communication may be changing and warrants future investigation.

The present study was the first to assess psychosocial and medical factors in adolescents with SCD within the context of a social support model. Overall current findings suggest that

understanding the impact of an adolescent's social environment on outcomes may involve many factors. Having similar friends may result in more support but what is learned from those friends may ultimately influence outcomes. Further, support may protect against feelings of loneliness in the hospital whereas an adolescent's experience of feeling stigmatized in their social environment may result in more loneliness as well as negative psychosocial and health outcomes. Lastly how friends interact with or respond to adolescents with SCD while in the hospital is important in the maintenance of friendships. Thus, findings stress the importance of considering and assessing social-contextual factors as these factors may have implications for psychosocial outcomes as well as health status during treatment. Current results also provide added evidence for the unfortunate relation between stigma and negative psychosocial and medical outcomes, which highlights the need for future investigation and development of interventions to address the impact of health-related stigma. Given the importance of the social context during adolescent development and the implications of healthy adolescent development for long-term health, further examination of social factors is warranted, especially in chronic illness populations that may be at risk for increased negative outcomes as a result of disease complications and illness-related stigma.

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APPENDICES

Appendix A. Measures

Background Information

Please tell us a about yourself by the checking the correct response or filling in the blank.

Questions about you:

1. Your Sex: ___Male ___Female
2. Your Age: ____ yrs. ____ mos.

3. Please select your ethnicity:

___Hispanic or Latino (A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race)

___Not Hispanic or Latino

4. Please select your race

___American Indian or Alaska Native — A person whose family is originally from any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

___Asian — A person whose family is originally from the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

___Black or African American — A person whose family is originally from any of the black racial groups of Africa.

If so, please check one:

____ From the Caribbean Islands
____ From South America
____ From Southern Africa
____ From Northern Africa
____ Other, please list: _____
____ Don't know

___Native Hawaiian or Other Pacific Islander — A person whose family is originally from any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

___White — A person whose family is originally from any of the original peoples of Europe, the Middle East, or North Africa.

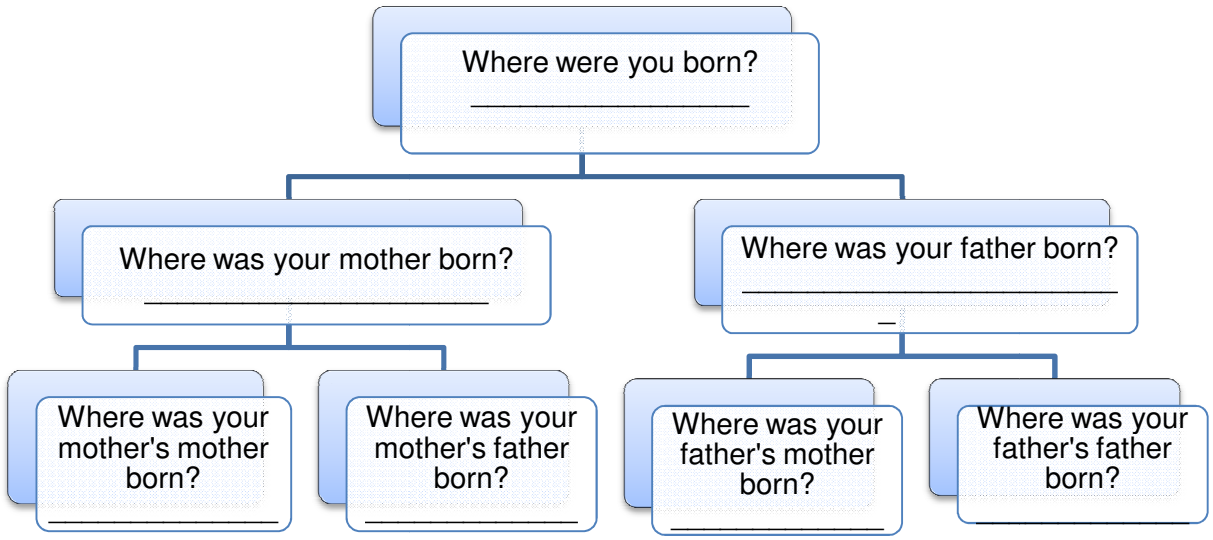
___ More than one race. Please list: _____

5. What type of SCD do you have?
___SS ___SC ___S-B Thal + ___S-B Thal 0 ___Don't Know ___Other:_____

6. What grade are you in at school? _____

Questions about your family

7. Please complete the family tree below and tells us in what *country* your parents and grandparents were born. If you don't know, just write "don't know."



8. Please circle your approximate total family income per year:

a. Up to $10,000
b. $10,001 – 20,000
c. $20,001 – 30,000
d. $30,001 – 40,000
e. $40,001 – 50,000
f. $50,001 – 60,000
g. $60,001 – 70,000
h. $70,001 – 80,000
i. $80,001 – 90,000
j. $90,000 and above
k. Don't know

Questions about your Pain

1. Please rate your average pain over the last 4 weeks. Draw a mark across the line below to tell us your answer.

No Pain ——————————————————— Worst Pain Ever

2. Please rate the worst pain you felt over the last 4 weeks. Draw a mark across the line below to tell us your answer.

No Pain ——————————————————— Worst Pain Ever

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Questions about your friends

1. How many close friends do you have? _____
2. How many of your friends also have SCD? _____

Communication

Questions about how often you talk to your friends <u>while you have been in the hospital</u>

With all of your close friends, *<u>since you have been in the hospital</u>*, how many *<u>total</u>* *<u>hours</u>* have you spent....	**Hours**
Emailing or sending messages on Facebook, MySpace, or other networking site?	_____
Texting or instant messaging?	_____
Talking on the phone?	_____
Video chatting?	_____
Talking through a gaming system while playing a video game?	_____
Having in person conversations?	_____

Child Stigma Scale

Please rate how answer the questions below to tell us how often you feel or act in the ways described in the items in the questions below.

	Never	Almost Never	Sometimes	Often	Very Often
1. How often do you feel different from other kids because you have sickle cell disease (SCD)?	1	2	3	4	5
2. How often do you feel people may not like you if they know you have a SCD?	1	2	3	4	5
3. How often do you feel other children are uncomfortable with you because of your SCD?	1	2	3	4	5
4. How often do you feel people may not want to be friends with you if they know you have SCD?	1	2	3	4	5
5. How often do you feel people would not want to go out with you or ask you to parties if they know you have SCD?	1	2	3	4	5
6. How often do you feel embarrassed about your SCD?	1	2	3	4	5
7. How often do you keep your SCD a secret from other kids?	1	2	3	4	5
8. How often do you try to avoid talking to other people about SCD?	1	2	3	4	5

PEDS-QL SCD Module
(Child and Teen Report 8-18)

DIRECTIONS
On this page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month.**

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.
In the past **ONE month**, how much of a **problem** has this been for you …

ABOUT MY PAIN and HURT ***(problems with…)***	**Never**	**Almost never**	**Sometimes**	**Often**	**Almost Always**
1. I hurt a lot	0	1	2	3	4
2. I hurt all over my body	0	1	2	3	4
3. I hurt in my arms	0	1	2	3	4
4. I hurt in my legs	0	1	2	3	4
5. I hurt in my stomach	0	1	2	3	4
6. I hurt in my chest	0	1	2	3	4
7. I hurt in my back	0	1	2	3	4
8. I have pain every day	0	1	2	3	4
9. I have pain so much that I need medicine	0	1	2	3	4

ABOUT MY PAIN IMPACT ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard for me to do things because I might get pain	0	1	2	3	4
2. I miss school when I have pain	0	1	2	3	4
3. It is hard for me to run when I have pain	0	1	2	3	4
4. It is hard to have fun when I have pain	0	1	2	3	4
5. I have trouble moving when I have pain	0	1	2	3	4
6. It is hard to stay standing when I have pain	0	1	2	3	4
7. It is hard for me to take care of myself when I have pain	0	1	2	3	4
8. It is hard for me to do what others can do because I might get pain	0	1	2	3	4
9. I wake up at night when I have pain	0	1	2	3	4

10. I get tired when I have pain	0	1	2	3	4
About my PAIN MANAGEMENT and CONTROL (problems with…)	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard for me to manage my pain	0	1	2	3	4
2. It is hard for me to control my pain	0	1	2	3	4
ABOUT MY WORRYING I (problems with…)	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I worry that I will have pain	0	1	2	3	4
2. I worry that others will not know what to do if I have pain	0	1	2	3	4
3. I worry when I am away from home	0	1	2	3	4
4. I worry I might have to go to the emergency room	0	1	2	3	4
5. I worry I might have to stay overnight in the hospital	0	1	2	3	4
ABOUT MY WORRYING II (problems with…)	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I worry that I might have a stroke	0	1	2	3	4
2. I worry that I might have a chest crisis	0	1	2	3	4
ABOUT MY EMOTIONS (problems with…)	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I feel mad I have sickle cell disease	0	1	2	3	4
2. I feel mad I have pain	0	1	2	3	4
ABOUT MY TREATMENT (problems with…)	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard for me to remember to take my medicine	0	1	2	3	4
2. I do not like how I feel after I take my medicine	0	1	2	3	4
3. I do not like the way my medicine tastes	0	1	2	3	4
4. My medicine makes me sleepy	0	1	2	3	4
5. I worry about whether my medicine is working	0	1	2	3	4
6. I worry about whether my treatments are working	0	1	2	3	4
7. My medicine does not make me feel better	0	1	2	3	4
ABOUT MY COMMUNICATION I (problems with…)	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard for me to tell others when I am in pain	0	1	2	3	4
2. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
3. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
ABOUT MY COMMUNICATION II (problems with…)	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard for me when others do not understand about my sickle cell disease	0	1	2	3	4
2. It is hard for me when others do not understand how much pain I feel	0	1	2	3	4

3. It is hard for me to tell others I have sickle cell disease	0	1	2	3	4

The Loneliness Questionnaire – Short Version
<u>In the Hospital</u>

Please indicate how much each statement is true about how you feel while you are in the hospital.

	Always True	**True most of the time**	**True sometimes**	**Hardly ever true**	**Not true at all**
1. I have no friends	1	2	3	4	5
2. I have no one to play with	1	2	3	4	5
3. I feel lonely	1	2	3	4	5
4. It is hard to get kids to like me	1	2	3	4	5
5. It's hard to make new friends	1	2	3	4	5
6. I have nobody to go to	1	2	3	4	5
7. I have nobody to talk to	1	2	3	4	5
8. I don't get along with others	1	2	3	4	5
9. I feel left out of things	1	2	3	4	5

Please answer the following question:

How does being in the hospital change your relationship or communication with your friends?”