Published in final edited form as:

J Natl Med Assoc. 2011 February ; 103(2): 131–137.

Disease Management, Coping, and Functional Disability in Pediatric Sickle Cell Disease

Gloria Oliver-Carpenter, PhD^{2,4}, Ilana Barach, B.A.^{2,3}, Lori E. Crosby, PsyD^{1,2}, Jessica Valenzuela, PhD^{1,2}, and Monica J. Mitchell, PhD^{1,2,3}

¹University of Cincinnati, College of Medicine

²Cincinnati Children's Hospital Medical Center, Division of Behavioral Medicine

³University of Cincinnati

⁴Department of Psychology, Northern Kentucky University

Abstract

Background—Youth with sickle cell disease (SCD) experience chronic symptoms that significantly interfere with physical, academic, and social-emotional functioning. Thus, to effectively manage SCD, youth and caregivers must work collaboratively to ensure optimal functioning. The goal of the current study was to examine the level of involvement in disease management tasks for youth with SCD and their caregivers. The study also examined the relationship between involvement in disease management tasks, daily functioning, and coping skills. The study utilized collaborative care and disease management theoretical frameworks.

Methods—Youth and caregivers participated in the study during an annual research and education day event. Forty-seven patients with SCD aged 6 to 18 years and their caregivers completed questionnaires examining level of involvement in disease management tasks, youth functional disability and youth coping strategies. Caregivers also completed a demographic and medical history form.

Results—Parents and youth agreed that parents are significantly more involved in disease management tasks than youth, although level of involvement varied by task. Decreased parent involvement was related to greater coping strategies used by patients, including massage, prayer, and positive thinking. Higher functional disability (lower functioning) was related to greater parent involvement in disease management tasks, suggesting that greater impairment may encourage increased parent involvement.

Conclusions—Health professionals working with families of youth with SCD should discuss with parents and youth how disease management tasks and roles will be shared and transferred during adolescence. Parents and youth may also benefit from a discussion of these issues within their own families.

Correspondence & requests for reprints should be directed to: Lori E. Crosby, PsyD, Associate Professor, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, MLC 3015, Cincinnati, OH 45229, PH: (513) 636-5380; Fax: (513) 636-7756; ; Email: Lori.Crosby@cchmc.org

All authors may be reached at: The University of Cincinnati, College of Medicine, Cincinnati Children's Hospital Medical Center, Division of Behavioral Medicine & Clinical Psychology, 3333 Burnet Ave, MLC 3015, Cincinnati, OH 45229, Phone: 513-803-0919; Fax: 513-636-7400, Lori.Crosby@cchmc.org.

Keywords

sickle cell disease; functional disability; coping

Sickle cell disease (SCD) is one of the most common genetically-inherited, hematological disorders, especially among African Americans, where the prevalence for the disease is 1 in 375.¹ Furthermore, this number is expected to rise due to immigration trends and heredity effects.¹ Given the prevalence rates of SCD, the need for interventions targeting disease management, as well as those increasing psychosocial functioning and coping in this population, will remain high.

Unique characteristics of SCD, such as debilitating pain episodes across the lifespan, impact daily functioning. In addition, patients with SCD must follow complex treatment regimens in order to manage their illness and to prevent pain episodes and other complications, including iron overload, organ damage, and infection¹. For children with SCD, this means that management requires close involvement by parents and medical professionals.^{2,3} Cultural, medical, and psychological factors related to SCD require collaborative, coordinated, and multi-disciplinary care among patients, parents, and health care providers to ensure that optimal health is achieved.⁴

The literature suggests that disease-management tasks should involve both the youth and caregiver, and that family roles should be developmentally appropriate.^{2,3} Research consistently indicates that someone in the family must take responsibility for disease-management tasks and medical adherence.^{5,6} Evidence suggests that poor management of SCD during adolescence results in an increased risk for medical complications and poor health outcomes in the future.^{7, 8} While youth involvement in disease management tasks has been studied in other populations, such as diabetes, cystic fibrosis, and human immunodeficiency virus,^{5,8-12} only a few studies have examined patient involvement in pediatric SCD,¹³⁻¹⁶ and these studies were specific to patient involvement in chelation therapy and pain management. The chelation studies found that parent involvement in chelation treatment is related to increased adherence. Similarly, there is evidence that youth and parent sharing of diabetes management tasks is associated with positive outcomes.⁴ Studies with other pediatric populations have found significant differences for patient involvement in disease management tasks based on demographic and disease variables (e.g., gender, age, illness variables, functional status). Youth may become more involved in illness management as they get older,^{5,11} but this transfer of responsibility to the adolescent may be based more on age than on youth readiness.⁹ Thus, existing research highlights the importance of better understanding parental involvement in relation to health outcomes in pediatric chronic diseases such as SCD.

Current models to improve disease-management behaviors and coping emphasize the importance of examining the level of parent support related to coping and functioning, particularly as the child gets older. For example, it may be that children with higher levels of functioning use more active coping strategies and are more involved in disease-management tasks. These questions are largely unexplored in pediatric SCD. The present study sought to

better understand parent and youth involvement in disease management in pediatric SCD, and how such involvement is related to coping and daily functional status.

Methods

Conceptualization of the Problem

The current study is one of the first to develop and pilot a measure of parent and youth involvement in general disease-management tasks in SCD. The study is based on two theoretical frameworks (see Figure 1). According to the model by Clark and Wong,⁹¹⁷ patient social support in disease management (parent/patient involvement in disease management in the current study) is related to the use of management strategies (coping in the current study). Both patient support variables and the use of management strategies are related to functional outcomes (functional disability in the current study). Thus, aim 1 of our study is to understand the relationship between youth and parent involvement in disease-management, while aim 2 is to examine the relationship between parent and youth involvement in disease-management tasks and coping. Aim 3 is to understand the relationship between patient and parent involvement in disease management, coping, and functional disability.

The Clark and Wong model can be understood within a broader collaborative care framework. Katon and colleagues¹⁸ pose that collaborative care, including patients and parents, is needed to ensure effective healthcare and positive health outcomes. This model states that beyond social support, it is the quality of collaborative care that will determine youth's day-to-day functioning. According to the model, we proposed 3 aims in this study:

1. To compare parent and youth involvement in disease-management tasks on a pilot measure adapted from the diabetes literature.
2. To assess the relationship between parent and youth involvement and youth coping strategies.
3. To assess the relationship between parent and youth involvement in disease-management tasks and youth daily functioning/ disability.

We predicted that parents would report significantly greater involvement in disease-management tasks than youth. Additionally, we predicted that youth and parent involvement in disease-management tasks would be negatively related to youth functional disability and positively related to youth coping strategies.

Study Design

This cross-sectional study used a convenience sample to examine key variables (i.e. descriptive statistics) and correlations to examine the relationships between them. One-hundred seventy-five youth between the ages of 6 and 18 years and their caregivers (parents, guardians or primary caregivers) were eligible for inclusion in the study. Youth were eligible if they had a diagnosis of SCD and were followed through the sponsoring institution's sickle cell clinic. Participants were recruited for this study as part of a larger research project during an annual Sickle Cell Disease Research and Education Day event. Sixty patients with

SCD and their caregivers (34% of individuals screened for eligibility) enrolled in the study. The current analyses included 47 of these participants (27% of eligible sample), which are representative of the larger study sample of 60 patients with respect to demographics, genotype, and medical history. To be used in the analyses, critical data elements had to be complete (parent completed involvement measures and 95% of other data).

Data Management

Informed consent was obtained from all participants, including parental permission and patient assent for youth age 11 and over. All participants were compensated with a gift card for their participation and time. Parents and youth completed the following measures independently:

Parent and Youth Involvement in Disease Management Scale for Pediatric sickle cell disease—The Parent and Youth Involvement Scale for Pediatric SCD is a parent- and youth-reported measure developed by the research team to assess level of involvement for daily disease-management tasks. This pilot measure was adapted from the Diabetes Family Responsibility Questionnaire, a widely used family measure.¹⁹ The purpose of the pilot measure was to assess parent and youth involvement in tasks related to pediatric SCD during a typical day. Respondents were asked to rate the level of parent and youth involvement on a 4-point scale, ranging from 1 (Does None), to 4 (Does Most). This measure has not yet been validated.²⁰ Parents/Caregivers and youth completed this questionnaire.

Coping Strategies Questionnaire-Revised (CSQ-R).²¹—The Coping Strategies Questionnaire-Revised (CSQ-R) is an 80-item questionnaire that measures how often participants use cognitive, behavioral, and physiologic coping strategies. Respondents rate the frequency with which they use each strategy on a 6-point Likert scale ranging from 1, “never use this strategy” to 6, “always use this strategy.” The CSQ-R produces 3 factor scores: (1) coping attempts, which measures “active” coping strategies such as talking with someone and “going on” despite pain; (2) negative thinking, which includes behaviors such as pessimistic thinking and worry; and (3) passive adherence, which includes behaviors such as praying, resting, and taking medications. The CSQ-R has been validated in pediatric SCD, and reliability coefficients for the 13 CSQ subscales²⁰ range from 0.69 to 0.91. Parents and youth (aged 13–18 years) completed this questionnaire. Parents were asked to complete the CSQ-R measure in reference to their child’s coping strategies (parent proxy report of child’s coping and not their own coping).

Functional Disability Inventory.²²—The Functional Disability Inventory (FDI) is a 15-item questionnaire that assesses perceived difficulty and the extent of restriction in performing common activities due to physical health. Inventory items assess disability across multiple domains including school, home, recreation, and social interactions. Parents and youth were asked to identify whether activities are 1) no trouble, 2) a little trouble, 3) some trouble, 4) a lot of trouble, or 5) impossible to do when the child is sick or not feeling well. Total FDI scores range from 0 to 60, with higher scores indicating greater disability. Acceptable internal consistency and test-retest reliability coefficients²¹ have been reported in

other pediatric populations ($\alpha = .94$). Parents and youth (age 13–18 years) completed the FDI.

Family Information Form—Parents completed a Family Information Form, which assessed demographic information and the patient's medical status. Parents were asked to report the number of clinic visits, emergency department visits, hospitalizations, school absences, and days in pain their child experienced over the past 12 months.

Statistical Analyses

All statistical analyses were conducted using PASW for Windows²³ version 17.0. In the analyses, responses that were left blank or marked as “not sure” were coded as “missing data”. Descriptive statistics were generated for demographics, type of SCD, healthcare utilization, days in pain, and days missed at school. A composite involvement score was generated for parents and youth. In addition, descriptive statistics were also generated for the two outcome variables of interest: functional disability and coping. Pearson correlations were utilized to examine the relationship between parent and youth involvement, youth functional disability, and youth coping strategies. The research protocol was approved by the Institutional Review Board of the sponsoring institution.

Results

Forty-Seven youth (48.9% female), ages 6 to 18 and their primary caregivers (80.4% mothers, 8.7% fathers, or other guardian) participated in the current study. The mean age of all youth was 11.93 years ($SD = 3.80$) and 53.2% of the patients were adolescents. SCD type was predominantly hemoglobin SS (HbSS 53.3%) and hemoglobin SC (HbSC 33.3%). The remaining participants (13.3%) had $S\beta^+Thal$ or $S\beta^0Thal$ genotypes. All patients self-identified as African American. Approximately one-third of the sample (33.3%) reported a family income of less than \$20,000, another third (35.7%) reported family income in the \$21,000–\$50,000 range, and the remainder reported family income above \$51,000 (31%). This sample was representative of all patients in the clinic with respect to age ($M = 11.86$, $SD = 3.87$), ethnicity (African-American = 99.07%) and genotype (HbSS = 50.3%). Demographic data for the sample, including information about medical status, are summarized in Table 1.

Youth and Caregiver Involvement

Average caregiver involvement ranged from $M = 3.08$ ($SD = 0.48$) based on youth report to $M = 3.29$ ($SD = 0.59$) based on parent-report, with 4 representing the highest level of involvement on a 4-point scale. Youth involvement ranged from $M = 2.39$ ($SD = 0.61$) based on self-report to $M = 2.51$ ($SD = 0.76$) based on parent report, also on a 4.0 scale. There were no significant differences in youth and parent report of involvement in disease-management tasks (youth and parents' perceptions of youth and parent involvement were not different). There were, however, overall differences in involvement, with both youth and parents rating parents' involvement as higher: parents reported greater parent involvement ($t = -5.50$; $p < .001$); youth-reported greater parent involvement ($t = -6.96$; $p < .001$).

Descriptive analyses conducted for individual disease-management tasks revealed that caregivers reported more involvement on most tasks than did youth, although rates varied (Table 2). In particular, caregivers took the lead on tasks such as remembering clinic appointments, telling teachers and relatives about SCD, and explaining school absences to school personnel. Interestingly, caregivers and youth reported similar levels of involvement for tasks such as remembering/reminding to drink fluids and taking vitamins.

Coping Strategies

Parents reported that youth primarily used passive coping strategies ($M = 3.82$, $SD = 1.32$ for *passive adherence*, which refers to behaviors such as praying, resting, and taking medication). Specifically, parents reported that youth used resting ($M = 3.86$, $SD = 1.57$), praying, and hoping ($M = 3.85$, $SD = 1.39$), heat/cold massage ($M = 3.74$, $SD = 1.63$), and calming self-statements ($M = 2.07$, $SD = 1.60$) most often. Positive coping attempts (eg, active coping strategies such as talking with someone or “going on” despite the pain; $M = 2.36$, $SD = 1.16$) and negative thinking (eg, behaviors such as pessimistic thinking and worry $M = 2.13$, $SD = 1.29$) were used less often.

Functional Disability

Parent-report of youth functional disability was lower (FDI Total Score: $M = 10.6$; $SD = 14.5$) than youth self-report of functional disability (FDI Total Score: $M = 19.2$; $SD = 15.2$), and this difference was statistically significant ($p < .05$). The top-rated challenges reported by parents and youth with respect to youth day-to-day functioning were related to physical limitations (i.e. running or walking the length of a football field, doing activities in gym/playing sports).

Relationship Involvement, Coping, and Functional Disability

All three subscales of the CSQ-R were related to youth reported parent involvement. Specifically, higher parent involvement by youth report was related to lower coping attempts ($r = -0.33$, $p = 0.04$), negative thinking ($r = -0.51$, $p = .00$), and passive adherence ($r = -0.46$, $p = .00$). Interestingly, youth report of higher parent involvement in disease-management tasks was related to higher functional disability (youth report on FDI) ($r = 0.40$, $p = 0.01$). This trend was also consistent with parent report of youth functional disability (parent report on FDI) ($r = 0.36$, $p = 0.02$).

Discussion

Managing a chronic illness such as SCD requires effective coordination of disease-management tasks within families. The current study is one of the first to examine how youth and caregivers manage disease-related tasks in SCD and how their level of involvement may be related to the coping and daily functioning. Parent involvement in disease-management tasks was rated higher by both parents and youth. However, descriptive analysis showed variability in how tasks were managed by both parties. While parents assume greater involvement for most tasks on average, data also show that levels of involvement range from limited involvement to high involvement across tasks. Parents appear to be highly involved in tasks related to treatment adherence such as making and

remembering appointments and remembering to take medicines, tasks for which youth reported little involvement (on average). Parents also appear to be more involved in communicating with others about the youth's disease-related needs (eg, telling teachers about SCD).

On tasks related to day-to-day functioning such as remembering to drink fluids, taking vitamins, and using pain coping strategies, the level of involvement for youth and parents was more similar. As youth mature to adolescence and adulthood, it will be essential that they take greater responsibility for making and remembering appointments, managing medications, noticing the early signs of acute pain episodes, and adjusting pain medications according to symptoms. These are tasks that parents reported being more involved in, but that adults with SCD will need to be responsible for to effectively self-manage. Thus, it will be important for parents to encourage adolescents to become more involved in these types of disease-management tasks as they mature. Health care providers are in a unique position to assist in this process by helping both parents and youth understand how to accomplish these tasks and suggesting ways in which parents can begin to shift responsibility for these tasks to youth during adolescence.

Adolescence is a time when youth gain autonomy from their parents,²⁴ and literature examining youth involvement in disease management in a variety of illness populations suggests that older youth tend to be more involved in their treatment.^{5,11} A post hoc analysis, however, revealed no significant relationship between age and parent involvement ($p > .05$). The finding may not be significant because parents may be transferring responsibility based on a range of factors, including developmental factors, disease severity, etc., and not age exclusively. For example, one study found that adolescent level of autonomy partially mediated the relationship between age and youth involvement in diabetes management.¹¹ Additionally, a limited sample size or the limited sensitivity of the disease-management measure may have contributed to the lack of difference in involvement by age group reported in this study.

Future research with a larger sample size should examine involvement/disease-management responsibilities over the course of childhood, adolescence, and into adulthood. As these studies emerge, we can better understand the age at which youth begin to manage medications independently in SCD and how this compares to other chronic illnesses. For example, large studies of children with asthma show that 50% of youth manage their medications⁵ by age 11, 75% by age 15, and 100% by age 19. Clinically, we know that although patients with SCD are becoming more independent in their disease-management responsibilities, adherence declines in adolescence and early adulthood.²⁵ Interventions are needed to ensure that caregivers and youth are optimally involved in disease management and that tasks are transferred to youth over time, while also promoting adherence with the treatment regimen.

This study found a relationship between levels of involvement in disease-management tasks (as rated by youth) and coping. All 3 scales on the CSQ-R were found to be significant suggesting that as parent involvement decreases, patient use of all three coping strategies increases. Youth engage in these strategies perhaps due to the lower support from their

parents regardless of how adaptive these strategies may be. The Coping Attempts Scale of the CSQ-R, for example, measures patient behaviors such as drinking fluids, taking medication, etc. So, it is understandable that as parents' involvement decreases, patients would do more of these behaviors on their own.

One trend, however, that was not expected was that youth with lower levels of parent support also engage in significantly higher levels of negative thinking compared to youth with higher levels of parental involvement. These trends highlight the importance of ensuring that youth are encouraged to not only use coping strategies but to use them adaptively as, according to the model, not all coping strategies will ensure a positive functional outcome. The findings confirm that it is important to strike a balance between parents providing support to youth while encouraging their independence. For example, there may be times when parents may play a leading role in disease management and other times when parents would play a supporting role, while youth may play a more active role in managing their disease.

The findings from the study are consistent with best practice in chronic illness coping which suggest that parent-child partnerships promote positive coping and efficacy in youth and reduce their anxiety related to their chronic disease. Future research can better discern whether parent disease-management styles develop because of youth's coping styles (e.g., negative thinking) or if youth's patterns of coping (e.g., negative thinking, passive adherence, etc.) develop in response to how involved parents are in their care management. Clinically, we know that parent-child relationships are dynamic and have an impact on disease management and health outcomes.²⁷ It will be important for medical staff to encourage parents to provide disease-management support while helping youth to develop positive and adaptive coping skills.

Finally, the study supported our hypothesis that parent and adolescent involvement was related to functional disability. Additionally, the level of functional disability in the sample was similar to rates reported in other pediatric populations, including patients with SCD²⁸ and chronic abdominal pain.²⁹ Data showed that youth who experienced greater challenges related to daily functioning also reported greater involvement in disease-management tasks. Youth with greater disability and their caregivers have likely had additional opportunities to practice disease-management tasks such as making appointments, recognizing physical signs related to pain, and increasing youth's fluid intake. It may be that families of youth with less physical limitations (lower functional disability) have less exposure to these types of tasks. This represents an opportunity for the healthcare team to provide anticipatory guidance to families about the how to's of disease management in case the family needs to use these skills in the future. Additional research is needed to explore how anticipatory guidance around disease-management tasks may be related to later treatment adherence and health outcomes. In addition, future larger scale and longitudinal studies can better discern the relationship between coping and functional disability, including whether coping predicts and mediates functioning, as described in the collaborative care model.

Study limitations should be acknowledged. This study adapted a measure of disease-management responsibility. Current measures are specific to other chronic illnesses (e.g. diabetes, asthma), making it difficult to use an existing standardized measure. As an

example, the items on an asthma questionnaire would be specific to using an inhaler, etc. As previously mentioned, the disease-management measure may lack the sensitivity required to detect clinically meaningful differences. Future larger-scale research is needed to validate and refine the measure piloted in this study and to further strengthen the clinical implications of the measure. One next step could be to better quantify youth and parent roles in disease-management tasks (eg, use activity logs or daily questionnaires to validate and quantify *who* is doing *what*). With more sensitive measures, we will be better able to discern the clinical meaning of the data. It is also important to note that factors such as disease severity and complexity of treatment regimen may have contributed to parent and youth involvement in disease management but were not measured in this study. Another limitation of the study is the small, convenience sample. The small sample size and wide age range, though comparable to other published studies in SCD, limits power in the study. With a larger sample size, a more fully stated theoretical model that leads to intervention can be tested. Such a study would allow for the next stages of hypothesis testing and the development of a theoretical model specific to SCD. The study would also provide a mechanism for understanding these variables across broader developmental, family systems, cultural, and collaborative care frameworks, providing directions for future research and clinical efforts.

The study's strengths include that it is one of the first studies on involvement and roles in SCD disease management, an important topic that has been explored in other pediatric chronic illnesses such as diabetes and asthma.⁴⁻⁶ Study results indicate that the adapted measure is feasible and yields clinically useful information. At an individual level, it was easy to note which youth or parents indicated no or little involvement on key disease-management tasks. Such information could serve as points of intervention of for families. Encouraging patient-parent collaboration is important whether or not patients have few or many disease-related symptoms. As an example, 40% of youth (patients of all ages) in this study reported that they have no involvement in remembering appointments. This provides information that would allow a health care team to work to increase involvement in appointment management for one patient or in a clinic sample over time.

In summary, study findings highlight the need to coordinate care with families, as well as with providers to ensure optimal health outcomes. The distribution of disease-management tasks within families should be an important component of discussions around adherence, transition to adult care, coping, family stress, and functional outcomes in pediatric SCD.

Acknowledgments

The authors would like to acknowledge Janelle Hines, Adryan Eastin and Candace Clark for their assistance with data collection and entry.

Financial Disclosure Statement: This study was funded by the National Institutes of Health/National Institutes of Diabetes and Digestive and Kidney Diseases T32 Training grant in Child Behavior and Nutrition (T32 DK063929) and National Institutes of Mental Health Career Development award (K01 MH64078).

References

1. Driscoll MC. Sickle Cell Disease. *Pediatrics in Review*. 2007; 28(7):259–268. [PubMed: 17601938]
2. Palermo TM, Chambers CT. Parent and family factors in pediatric chronic pain and disability: An integrative approach. *Pain*. 2005; 119:1–4. [PubMed: 16298492]

3. Wallander JL, Varni JW, Babani L, Banis HT, Wilcox KT. Children with chronic physical disorders: Maternal reports of their psychological adjustment. *Journal of Pediatric Psychology*. 1989; 13:197–212. [PubMed: 3171813]
4. J V. A Comprehensive Program for Meeting Psychosocial Needs of Sickle Cell Anemia Patients. *J Natl Med Assoc*. 1977; 69(5):335–339. [PubMed: 864774]
5. Drotar D, Ievers C. Preliminary report: Age differences in parent-child responsibilities for management of cystic fibrosis and insulin-dependent diabetes mellitus. *Journal of Developmental and Behavioral Pediatrics*. 1994; 15:367–374. [PubMed: 7868705]
6. Orrell-Valente J, Cabana M. The apple doesn't fall far from the tree': the role of parents in chronic disease self-management. *Current Opinion in Pediatrics*. 2008; 20(6):703–704. [PubMed: 19005339]
7. Dampier C, Ely E, Brodecki D, O'Neal P. Home management of pain in sickle cell disease: A daily diary study in children and adolescents. *Journal of Pediatric Hematology/Oncology*. 2002; 24(8): 643–647. [PubMed: 12439036]
8. Logan DE, Radcliffe J, Smith-Whitley K. Parent factors and adolescent sickle cell disease: associations with patterns of health service use. *Journal of Pediatric Psychology*. 2002; 27(5):475–484. [PubMed: 12058011]
9. Clark NMWM. Management of chronic disease by practitioners and patients: are we teaching the wrong things?. 2000
10. SPSS for Windows version 17.0 [computer program]. Chicago, Illinois: 2010.
11. Orrell-Valente JKJL, Hill LG, Cabana MD. At what age do children start taking daily asthma medicines on their own? *Pediatrics*. 2008; 122(6):e1186–e1192. [PubMed: 19047221]
12. D D. Physician behavior in the care of pediatric chronic illness: association with health outcomes and treatment adherence. *J Dev Behav Pediatr*. 2009; 30(3):246–254. [PubMed: 19525719]
13. Kieckhefer GMTCC, Churchill SS, Simpson JN. Measuring parent-child shared management of chronic illness. 2009; 35(2):101–108.
14. Anderson BJ, Ho J, Brackett J, Finkelstein D, Laffel LMB. Parental Involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with IDDM. *Journal of Pediatrics*. 1997; 130:257–265. [PubMed: 9042129]
15. Treadwell MJ, Weissman L. Improving adherence with DFO regimens for patients receiving chronic transfusion therapy. *Semin Hematol*. 2001; 38:77–84. [PubMed: 11206966]
16. Beyer JE, Simmons LE. Home treatment of pain for children and adolescents with sickle cell disease. *Pain Manage Nurs*. 2004; 5:126–135.
17. Clark NM, Gong M. Management of chronic disease by practitioners and patients: are we teaching the wrong things? *BMJ*. 2000; 320:572–575. [PubMed: 10688569]
18. Katon WJ, Von Korff M, Lin EHB, Simon G, et al. The Pathways Study: a randomized trial of collaborative care in patients with diabetes and depression. *Arch Gen Psychiatry*. 2004; 61:1042–1049. [PubMed: 15466678]
19. Anderson BJ, Auslander WF, Jung KC, Miller JP, Santiago JV. Assessing family sharing of diabetes responsibilities. *J Pediatr Psychol*. 1990; 15:477–492. [PubMed: 2258796]
20. Carpenter, GJO.; Akhalq, S.; Hines, J.; Crosby, L.; Mitchell, MJ. Patient and parent responsibilities and involvement in sickle cell disease management strategies. Paper presented at: Regional Conference on Child Health Psychology; Cincinnati, OH. 2007.
21. Gil KM, Abrams MR, Phillips G, Keefe FJ. Sickle cell disease pain: Relation of coping strategies to adjustment. *J Consult Clin Psychol*. 1989; 57:725–731. [PubMed: 2600243]
22. Walker LS, Greene JW. The functional disability inventory: measuring a neglected dimension of child health status. *J Pediatr Psychol*. 1991; 16:39–58.
23. SPSS for Windows version 17.0 [computer program]. Chicago, IL: 2010.
24. Beveridge RM, Berg CA. Parent-adolescent collaboration: An interpersonal model for understanding optimal interactions. *Clin Child Fam Psychol Rev*. 2007; 10:25–52. [PubMed: 17351747]
25. Drotar D. Physician behavior in the care of pediatric chronic illness: association with health outcomes and treatment adherence. *J Dev Behav Pediatr*. 2009; 30:246–254. [PubMed: 19525719]

26. Mitchell MJ, Lemanek K, Palermo TM, Crosby LE, Nichols A, Powers SW. Parent perspectives on pain management, coping, and family functioning in pediatric sickle cell disease. *Clin Pediatr*. 2007; 46:311–319.
27. Kieckhefer GM, Churchill SS, Trahms CM, Simpson JN. Measuring parent child shared management of chronic illness. *Pediatr Nurs*. 2009; 35:101–108. [PubMed: 19472673]
28. Palermo TM, Riley CA, Mitchell BA. Daily functioning and quality of life in children with sickle cell disease pain: Relationship with family and neighborhood socioeconomic distress. *J Pain*. 2008; 9:833–840. [PubMed: 18550443]
29. Claar RL, Walker LS. Functional assessment of pediatric pain patients: Psychometric properties of the functional disability inventory. *Pain*. 2006; 121:77–84. [PubMed: 16480823]

* Based on Clark and Gong Model ** Based on Katon model. ^c Unable to assess these factors due to sample size limitations.

Figure 1.
Theoretical Model Based on Disease Management^{17,1} and Collaborative Care Models¹⁸

Table 1

Summary of Patient Demographics

Patient Characteristics	Mean (SD)
Age	11.93 (3.80)
Clinic Visits (average in past 12 mo)	4.65 (6.07)
ER Visits (average in past 12 mo)	2.51 (6.61)
Hospitalizations (average in past 12 mo)	1.68 (4.39)
School absences (average in past school year)	10.79 (13.60)

Table 2

Mean Ratings of Youth and Parent Ratings of Involvement in Disease-Management Tasks (n =47)

Management Task	Parent Self Report	Parent Youth Report	Youth Parent Report	Youth Self Report
Overall Means	3.29 (0.59)	2.51 (0.76)	3.08 (0.47)	2.38 (0.61)
Remembering day of clinic appointment	3.94(0.25) *	2.23 (1.24)	3.68 (0.72) *	2.17(1.22)
Telling teachers about SCD	3.79(0.59) *	2.56 (1.12)	3.56 (0.85) *	2.25(1.18)
Telling friends about SCD	3.27(1.05)	2.66 (1.20)	2.34 (1.26)	2.33(1.22)
Remembering to take medications	3.41(1.00)	2.74 (1.22)	3.43 (0.98)	2.83(1.16) *
Making Appointments with other doctors	3.87(0.45) *	1.87 (1.26)	3.83 (0.56) *	1.71(1.15)
Telling relatives about SCD	3.85(0.42) *	2.48 (1.15)	3.39 (0.94)	2.46(1.27)
Taking more or fewer pain medications according to pain and other symptoms	3.40(0.88)	2.43 (1.19)	3.40 (0.95)	2.19(1.12)
Noticing differences in health such as weight changes or signs of infection	3.62(0.65)	2.64 (1.18)	3.39 (0.84)	2.33(1.20)
Noticing early signs of acute crisis	3.40(0.95)	2.96 (1.10) *	3.17 (1.07)	2.75(1.16) *
Deciding what to eat at meals or snacks	3.47(0.79)	2.83 (1.04) *	3.00 (1.01)	2.97(1.18) *
Carrying over-the- counter meds in case of pain/illness	3.17(1.10)	2.06 (1.20)	3.58 (0.77) *	2.25(1.20)
Explaining school absences to teachers	3.72(0.72) *	2.17 (1.17)	3.36 (1.07)	2.06(1.26)
Remembering to drink fluids	3.56(0.84)	3.40 (0.83) *	2.88 (1.20)	3.40(0.81) *
Taking vitamins and minerals	2.73(1.37)	2.39 (1.26)	2.67 (1.28)	2.42(1.30)
Checking expiration dates on med supplies	3.68(0.75)	2.80 (1.31) *	3.52 (0.91) *	1.94(1.22)
Finding strategies to manage pain	3.28(1.02)	2.80 (1.24) *	3.00 (1.10)	2.81(1.09) *

* Tasks for which parents or youth rated highest levels of involvement

Table 3

Patient Involvement, Functional Disability, and Coping Skills

	Parent Involvement (Patient Report)	Patient Involvement (Parent Report)
FDI - functional disability	0.362 *	0.397 **
CSQ-R - coping attempts	-0.331 *	0.185
CSQ-R - negative thinking	-0.513 **	0.204
CSQ-R - passive adherence	-0.457 **	0.056

Notes:

* = significant at $p < .05$,** = significant at $p < .01$