

A Longitudinal Examination Predicting Emergency Room Use in Children with Sickle Cell Disease and Their Caregivers

Ronald T. Brown,¹ PhD, Mark Connelly,² PhD, Carrie Rittle,³ BS, and Barbara Clouse,⁴ PhD

¹Department of Public Health, Temple University, ²Department of Psychiatry and Behavioral Sciences, Duke University, ³The Citadel, and ⁴Medical University of South Carolina

Objective To examine in a longitudinal investigation perceptions of disease severity among children and adolescents with sickle cell disease (SCD) and their caregivers and to determine whether perceptions of disease severity and self-reported adjustment would account for a greater percentage of the variance in emergency room (ER) use than objective measures of disease severity. **Methods** Participants were 58 African-American children (ages 8–18 years) diagnosed with SCD who were recruited from an outpatient clinic. Children and their caregivers were administered a series of measures designed to assess caregivers' adjustment and perceptions of children's disease severity. Frequency of ER visits was tabulated over an average 4-year period. **Results** Caregivers' and children's social adjustment accounted for a unique portion of the variance beyond that accounted by subjective perceptions of disease severity, demographic, and objective biological markers of disease severity. Poorer psychological adjustment of caregivers as well as communication patterns among children were associated with ER use frequency after controlling for objective disease severity variables and demographic factors. Child social adjustment, specifically friendship quality, accounted for variance in children's use of the ER beyond that accounted for by social class and objective markers of disease severity. **Conclusions** Support is provided for the notion that ER use for children with SCD may be independent of disease severity and predicted by caregivers' psychological adjustment and children's peer adjustment.

Key words emergency room utilization; perceptions of disease; sickle cell disease.

Sickle cell disease (SCD) is a chronic condition occurring in both children and adults that is characterized by debilitating pain episodes, stroke, anemia, major organ failure, as well as other serious comorbidities. The disease almost always requires lifelong management and ongoing utilization of health care resources. There is significant variability in disease presentation with severity of SCD determined by the type of disease present. HbSS (homozygous for the SB genes) is the most severe type; HbS (protein hemoglobinS in red blood cells) beta-thalassemia is the least severe type of hemoglobinopathy. In addition, there is some mounting evidence to

suggest that severity of anemia is predictive of disease severity, particularly among those with the most severe type of disease presentation (HbSS) (Brown, Mulhern, & Simonian, 2002).

Over the past several decades, there has been significant interest in the association between disease severity for many pediatric chronic illnesses and children's adjustment. Some investigators have found a significant association between disease severity and adjustment difficulties for many chronic illnesses (for review see, Brown & Macias, 2001; Thompson & Gustafson, 1996), whereas other studies have failed to support such a

All correspondence concerning this article should be addressed to Ronald T. Brown, Dean, Temple University, College of Health Professions, 3307 North, Broad Street, Philadelphia, Pennsylvania 19140-5101. E-mail: ronald.brown@temple.edu.

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relationship (Brown & Macias, 2001; Thompson & Gustafson, 1996). The association between adjustment and chronic illness is important as adjustment has been demonstrated to be associated with the appropriate use of health care resources (for review see, Brown et al., 2002; Janicke & Finney, 2001).

For disease severity and adjustment, it has been suggested that perceptions of disease severity may be a more viable predictor of psychosocial outcome than specific markers of objective disease severity (Boekaerts & Roder, 1999; Middence & Elander, 1994). For example, Schaeffer et al. (1999) found that adult patients with SCD who reported more frequent painful episodes were apt to report more depressive symptoms. For pediatric patients in particular, the findings regarding perceptions of disease severity on the part of either the caregiver or the child are important as these perceptions may predict important patterns of emergency room (ER) use among specific chronic illness groups including children and adolescents with SCD (for review see, Brown & Macias, 2001).

Specifically, given the association between perceptions of disease severity and adjustment (Connelly et al., 2004), there has been a dearth of studies in the pediatric literature that has examined psychological adjustment, perceptions of disease severity (e.g., pain intensity), and health care utilization patterns. Specifically, for children and adolescents with SCD, Gil, Williams, Thompson, and Kinney (1991) found that children who reported high negative thinking were more psychologically distressed during painful episodes and also required more health services. Further, increased parental perceptions of child vulnerability were associated with greater social anxiety in children even after controlling for disease severity (Anthony, Gil, & Schanberg, 2003).

For health care utilization, when objective measures of disease severity were controlled, patients' perceived adjustment has been found to be the most salient predictor of health care utilization patterns among adults with SCD (Grant, Gil, Floyd, & Abrams, 2000). Similarly, Gil, Abrams, Phillips, and Williams (1992) in a longitudinal investigation of adults with SCD found that negative thinking was associated with more frequent reported pain episodes and a higher incidence of health care contacts during the subsequent 9 months. In a recent investigation among African-American adults with SCD, Gil and her associates (Gil et al., 2004) found daily ratings of positive mood to be associated with lower pain ratings as well as fewer health care contacts. These data underscore the role of patient perceived adjustment and vulnerabilities in predicting health care utilization among

adults with a chronic disease. For pediatric populations, specifically, there has been some research to suggest that parental psychopathology is an important predictor of high frequency pediatric health care utilization (Kelleher & Starfield, 1990; Riley et al., 1993; Ward & Pratt, 1996). Further, both internalizing and externalizing behaviors, problems with peer interactions and difficulties at school have been found to be associated with high health care utilization among children. In an examination of social-cognitive influences on parent decision-making processes related to children's health care use, Janicke and Finney (2003) demonstrated that parental stress, child behavior problems, and self-efficacy to cope accounted for nearly 30% of the variance in primary care use. However, no studies can be located that have examined perceptions of disease severity among both caregivers and children with SCD and the role of psychosocial adjustment among both informants simultaneously in predicting health care utilization.

The purpose of the present investigation was to expand the work of Gil and associates by examining perceptions of disease severity while controlling for objective measures [i.e., type of hemoglobinopathy (HbSS, HbSC, Hb beta-thalassemia), hemoglobin levels] among both children and adolescents with SCD and their caregivers. In addition, adjustment of both caregivers and children with SCD was examined as this influenced ER utilization (i.e., use of ER facilities). The study is unique as it is longitudinal and followed the children and adolescents prospectively. It was hypothesized that perceptions of disease severity among both caregivers and children as well as self-reported adjustment among caregivers and children with SCD each would account for a significant percentage of the variance in ER use above and beyond that accounted for by than objective measures of disease severity. Researchers predicted that poorer adjustment for both caregivers and children would be associated with greater frequency of ER use.

Method

Participants

Participants were 58 African-American patients (33 female, 25 male) between the ages of 8 and 18 years ($M = 11.8$, $SD = 2.77$) who attended the outpatient sickle cell clinic at a large health sciences center in the southeastern part of the United States over the course of a 4-year period. Most of the caregivers of the participants for this sample were the biological mothers of the children ($n = 49$; 84%), followed by biological fathers ($n = 7$; 12%), grandmother ($n = 1$; 2%), and aunt ($n = 1$,

2%). The average maternal and paternal educational attainment was a high-school diploma; fewer than 10% attended college. Children were typically diagnosed with the most severe cases (sickle cell anemia or HbSS; $n = 45$; 77%), followed by the less severe types of sickle cell hemoglobin C (HbSC; $n = 8$; 14%), and sickle beta-thalassemia (HbS beta-thalassemia (two abnormal beta-globin genes); $n = 5$; 9%). Age of diagnosis is almost always 6 months or younger; reported age at initial symptom onset ranged from birth to 6 years ($M = 0.97$ years, $SD = 1.33$).

Measures

Demographics

The investigators developed a brief questionnaire. Caregivers answered questions about paternal and maternal educational attainment and current occupation, children's age at symptom onset, type of classroom in which the child was currently placed (i.e., self-contained special education, regular placement with resource help, and regular classroom without resource help), and medications the child was currently receiving.

Because most caregivers were mothers, maternal education was used as a proxy index of family socioeconomic status (SES).

Objective Ratings of Disease Severity

The medical charts of participating children were reviewed for type of SCD (i.e., HbSS, HbSC, HbS beta-thalassemia) and hemoglobin levels over the child's last three consecutive clinic visits.

The frequency of ER visits since the patient initially enrolled into the study was the measure used as a proxy for health care utilization. As a means of controlling for the length of time that children were enrolled in the study, ER visits were averaged for a 12-month period. Frequency of ER visits was obtained from a computerized data base tracking contacts with the university hospital. Because this hospital was the only facility available in the region for these children with SCD and their families, it is unlikely that they sought medical treatment elsewhere.

Perceptions of Disease Severity

A brief questionnaire was developed to assess children's and caregivers' perceptions of disease severity. The child version of the questionnaire asked children to rate their symptom severity, functional limitations (e.g., not able to engage in sports, difficulty maintaining social relationships with friends, difficulty attending school), and

pain level by using a 100 mm visual analog scale. The caregiver version was on an identical metric and asked the caregiver to rate the child's disease severity, functional limitation, and pain level. Caregiver and child responses were averaged separately to form a composite measure of subjective perceptions of disease severity; with an acceptable internal consistency estimate (average Cronbach's $\alpha = .66$).

Measure of Caregiver Adjustment

The Symptom Checklist-90-Revised Scale (SCL-90-R) (Derogatis, 1983) was used to evaluate caregivers' level of psychological distress. The SCL-90-R is a self-report measure in which respondents rate how much a given problem has distressed them in the past week using a 0 (not at all) to 4 (extremely) scale. The SCL-90-R measures depression, hostility, psychoticism, somatization, obsessive-compulsive symptoms, interpersonal sensitivity, anxiety, phobic anxiety, and paranoid ideation. It is used extensively for research and clinical purposes and has good reliability, validity, and cultural sensitivity (Brown, Doepke, & Kaslow, 1993; Derogatis, 1983; Thompson, Gil, Burbach, Keith, & Kinney, 1993). The grand total of the SCL-90-R was used in analyses.

Child Adjustment

For the purpose of assessing child adjustment in this investigation, researchers decided to employ specific narrow band measures of social adjustment because the literature has cast doubt regarding the use of broad band measures of adjustment in children and adolescents with chronic illness (Perrin, Stein, & Drotar, 1991).

Social Anxiety

The revised edition of the Social Anxiety Scale for Children (SASC-R; La Greca, Dandes, Wick, Shaw, & Stone, 1988) was used as one index of social adjustment. The SASC-R is a 22-item measure designed to assess anxiety in children in relation to social interactions. Children are asked to respond to various statements using a 5-point scale (not at all true to always true). Examples of items include "I feel shy around kids I don't know" and "I worry about what other kids think of me." The SASC-R yields a total scaled score in addition to three factor-derived subscale scores: fear of negative evaluation, social avoidance and distress—specific, and social avoidance and distress—general. Good internal consistency for the instrument and a capability of discriminating neglected and rejected children from a group of normally developing comparison controls were reported by La Greca and Stone (1993). Utility of the SASC-R

in pediatric populations has been reported (Pendley, Dahlquist, & Dreyer, 1997; Varni, Katz, Colegrove, & Dolgin, 1995). Internal consistency (Cronbach's α) for the total scale based on the sample in this study was .86, indicating good reliability.

Loneliness

The Asher Loneliness Questionnaire (Asher, Hymel, & Renshaw, 1984) is a 24-item, self-report measure evaluating social dissatisfaction in children. Participants are asked to respond to various statements using a 1 (not at all true) to 5 (always true) scale. Sample items include "It's hard for me to make friends" and "I don't have anyone to have fun with." Internal consistency and predictive validity were supported by Asher et al. (1984) and by Asher and Wheeler (1985). Of the 24 items, 16 load on a single factor; the remaining 8 are filler items. Internal consistency (Cronbach's α) based on the current sample was good (.84).

Friendship Quality

The Friendship Qualities Scale (Bukowski, Hoza, & Boivin, 1994) is a 23-item self-report questionnaire designed to assess a child's impression of her or his relationship with a best friend. The child is asked to think about his or her best friend and respond to statements about companionship, conflict, help, closeness, and security using a 5-point rating scale ranging from "not at all true" to "always true." Subscale and total scaled scores can be computed. Bukowski and colleagues have reported acceptable internal consistency (above .70 for all subscales and the total scale) and good convergent validity with stable and mutual friendships. Cronbach's α for the total scale in the current sample was .88, suggesting quite good reliability.

Procedure

All families were recruited from an outpatient pediatric sickle cell clinic. Families were approached during a routine medical follow-up appointment and asked to participate in a study evaluating the effect of SCD on children's social adjustment. Prospective participants were informed that the study required approximately 1 hr of their time during which both the caregiver and child would complete a set of questionnaires. Families were also told that they would receive \$10 for their participation. Using forms approved by the Institutional Review Board at the health sciences center, informed consent was obtained from interested caregivers and assent was obtained from the children. Five families refused participation in this investigation because of time constraints. Participating caregivers and children were

asked to complete the set of questionnaires independently in the examination room. A member of the research team assisted younger children (less than 10 years old) with reading the items on the questionnaires. ER utilization was initially obtained by means of chart reviews. The participants were subsequently tracked for ER use over a period (Range = 29–61 months; $M = 46.48$ months, $SD = 9.48$ months). The frequency of ER use was averaged for each participant for a 12-month period.

Data Analysis

Predictors of ER utilization were assessed through hierarchical multiple regression models. Two control variables were considered for entry into the first step of each model based on theoretical importance: participant age (to control for the effects of disease duration given that the disease is generally diagnosed within the first 6 months of life) and SES (to control for potential accessibility differences in ER use). However, only SES was retained in regression models given that age was unrelated to ER utilization in zero-order correlations. On the next step of the regression models, two additional variables were added: The objective disease severity indices of averaged hemoglobin and disease subtype (dummy coded) were force entered to determine the extent to which these objective variables of disease severity were predictive of ER use, given that these variables are generally considered before psychosocial variables for ER utilization. Researchers then evaluated the extent to which caregiver psychological adjustment (SCL-90-R grand total), child social adjustment (SASC-R total, Asher Loneliness total, and Friendship Qualities total), and subjective perceptions of disease severity (composite scores) predicted utilization beyond demographics and objective severity indicators by evaluating changes in proportions of variance accounted for. Models were first evaluated separately for caregiver and children data, and subsequently a combined model was evaluated to compare the relative predictive power of the adjustment and perceptions of disease severity measures for caregivers and children. Researchers used stepwise entry for the three child social adjustment variables given no a priori assumptions about the relative predictive power of these variables. Criteria for stepwise entry were set to a p value of .10 and criteria for stepwise removal were set to a p value of .15. Many variables entered into each of the equations did not exceed the minimum ratio of cases to variables (10–1) as recommended by Pedhazur (1997) so as to assure the reliability of regression equations across samples.

Results

Table I summarizes zero-order correlations and descriptive statistics on the demographic, medical, and psychosocial variables for the child and caregiver data. The variable comprising the number of ER visits per year was found to be highly leptokurtic and positively skewed; researchers therefore used a square root normalization transformation and conducted analyses using the transformed variable.

Caregiver Adjustment and Perception of Disease Severity

Table II summarizes the results of the regression analyses performed on the caregiver data. The total model incorporating the demographic, objective disease severity, caregiver adjustment, and caregiver subjective perception of disease severity variables was significant, $R^2 = 0.19$, $F(5, 52) = 2.37$, $p = .05$. The composite measure of caregiver perception of disease severity did not incrementally predict ER utilization over and above the demographic, objective disease severity, and adjustment variables, R^2 change = 0.03, $F(1, 52) = 1.78$, ns .

Researchers subsequently reverse entered the adjustment and subjective perception of disease severity

variables to evaluate the predictive power of informant adjustment above and beyond subjective perceptions of disease. Results of this analysis indicated that caregiver adjustment tended to be predictive of ER utilization above and beyond variance accounted for by subjective perceptions of disease severity and the demographic and objective disease severity variables, R^2 change = 0.06, $F(1, 52) = 3.68$, $p = .06$. The direction of the relationship suggested that poorer caregiver psychological adjustment was related to more frequent ER utilization after controlling for the demographic and objective and subjective disease severity variables.

Child Social Adjustment and Perception of Disease Severity

Table III summarizes the results of the regression analyses performed on the child data. The linear combination of the demographic, objective, and subjective disease severity, and child social adjustment variables was significantly related to ER utilization, $R^2 = 0.26$, $F(5, 52) = 3.64$, $p < .01$ (Table III). Of the child social adjustment variables, perceptions of friendship quality (Friendship Qualities Scale total score) met the stepwise criteria for entry and accounted for a significant proportion of variance

Table I. Zero-Order Correlations and Descriptive Statistics of the Demographic, Objective Disease Severity, and Child-Reported Subjective Disease Severity and Social Adjustment Variables

Variable	1	2	3	4	5	6	7	8	9	10	11
Demographic											
1. Age	—										
2. Socioeconomic status	.05	—									
Objective disease severity											
3. Hemoglobin	-.26*	.09	—								
4. Disease subtype	-.18	.07	.62*	—							
Child social adjustment											
5. Child social anxiety	.04	.01	-.22**	.04	—						
6. Child loneliness	-.03	.08	-.05	.20	.53*	—					
7. Child friendship quality	.05	-.01	-.03	.06	-.13	-.26*	—				
Child perceptions of disease severity											
8. Subjective disease severity	.14	-.03	-.14	-.02	.24**	-.08	.08	—			
Caregiver psychological adjustment											
9. Symptom Checklist-90-Revised Scale grand total	-.14	-.01	.08	.17	.15	-.04	.08	.08	—		
Caregiver perceptions of disease severity											
10. Subjective disease severity	.15	-.16	.03	.02	.13	.11	-.20	.32*	.05	—	
Utilization											
11. Emergency room utilization/year	.02	.29*	.08	.06	-.16	-.07	.29*	.89*	.24**	.13	—
M	12.32	12.29	9.09	NA	46.85	31.43	93.19	40.74	52.54	51.43	1.15
SD	2.77	1.38	1.54	NA	13.86	11.13	16.22	26.77	13.15	26.90	1.44

NA, Not applicable.

*Significant at $p < .05$ level. **Trend at $p < .10$ level.

Table II. Model Fit and Beta-Weight Indices Based on Regression Analyses Predicting Emergency Room (ER) Utilization from Caregiver Data

Variable	<i>B</i>	<i>SE B</i>	β	<i>R</i> ²	ΔR^2
Step 1				.09*	—
Socioeconomic status	.10*	.04	.31		
Step 2				.10	.00
Socioeconomic status	.09*	.04	.30		
Subtype/hemoglobin	.03/.01	.17/.05	.03/.02		
Step 3				.16**	.06**
Socioeconomic status	.09*	.04	.31		
Subtype/hemoglobin	-.02/.01	.17/.05	-.02/.04		
Symptom Checklist-90-Revised Scale grand total	.01**	.01	.25		
Step 4				.19*	.03
Socioeconomic status	.10*	.04	.32		
Subtype/hemoglobin	-.03/.01	.16/.04	-.03/.04		
Symptom Checklist-90-Revised Scale grand total	.01**	.01	.25		
Subjective disease severity	.00	.00	.17		
Step 4 reverse entered				.19*	.06**
Socioeconomic status	.10*	.04	.32		
Subtype/hemoglobin	-.03/.01	.16/.04	-.03/.04		
Subjective disease severity composite score	.00	.00	.17		
Symptom Checklist-90-Revised Scale grand total	.01**	.01	.25		

Significance tests were computed for the unstandardized regression coefficients (*B*), overall model (*R*²), and change statistic (ΔR^2). Disease subtype was dummy coded, with the lower number reflecting the most severe subtype (HbSS) and the higher number reflecting the less severe subtypes (HbSC and HbS beta-thalassemia combined). *Significant at *p* < .05 level. **Trend at *p* < .10 level.

Table III. Model Fit and Beta-Weight Indices Based on Regression Analyses Predicting Emergency Room (ER) Utilization from Child Data

Variable	<i>B</i>	<i>SE B</i>	<i>B</i>	<i>R</i> ²	ΔR^2
Step 1				.09*	—
Socioeconomic status	.10*	.04	.31		
Step 2				.10	.00
Socioeconomic status	.09*	.04	.30		
Subtype/hemoglobin	.03/.01	.17/.05	.03/.02		
Step 3				.19*	.10*
Socioeconomic status	.10*	.04	.30		
Subtype/hemoglobin	-.01/.02	.16/.04	-.01/.06		
Friendship qualities total	.01*	.00	.31		
Step 4				.26*	.03*
Socioeconomic status	.10*	.04	.31		
Subtype/hemoglobin	-.04/.03	.16/.04	-.04/.11		
Friendship qualities total	.01*	.00	.34		
Subjective disease severity	.01*	.00	.26		
Step 4 reverse entered				.26*	.11*
Socioeconomic status	.10*	.04	.31		
Subtype/hemoglobin	-.04/.03	.16/.04	-.04/.11		
Subjective disease severity	.01**	.00	.26		
Friendship qualities total	.01*	.00	.34		

Significance tests were computed for the unstandardized regression coefficients (*B*), overall model (*R*²), and change statistic (ΔR^2). Disease subtype was dummy coded (“HbSS” and “other”).

*Significant at *p* < .05 level. **Trend at *p* < .10 level.

above and beyond the demographic and objective and subjective disease severity variables, *R*² change = 0.11, *F*(1, 52) = 7.74, *p* < .01. The direction of the relationship indicated that child-reported friendship quality was positively associated with ER utilization.

When reverse entering the child social adjustment and child perceptions of disease variables, child-reported subjective perceptions of disease severity was also significantly predictive of ER utilization beyond the demographic, objective severity, and social adjustment variables, *R*² change = 0.07, *F*(1, 52) = 4.67, *p* = .03. The direction of the relationship indicated that higher subjective perceptions of disease severity were related to more frequent ER utilization. Child social adjustment and subjective perceptions of disease severity were therefore each independently significantly predictive of ER utilization.

Combined Caregiver and Child Model

Table IV summarizes the results of the regression analyses performed on the combined child and caregiver data. The significant (*p* < .10) predictors from the independent caregiver and child models were entered into a combined model to determine the relative contribution of caregiver and child variables in the prediction of ER utilization. SES was entered on the first step, followed by

Table IV. Model Fit and Beta-Weight Indices Based on Regression Analyses Predicting Emergency Room (ER) Utilization from Combined Child and Caregiver Data

Variable	<i>B</i>	<i>SE B</i>	β	<i>R</i> ²	ΔR^2
Step 1				.09*	—
Socioeconomic status	.10*	.04	.31		
Step 2				.10	.00
Socioeconomic status	.09*	.04	.30		
Subtype/hemoglobin	.03/.01	.17/.05	.03/.02		
Step 3				.31*	.21*
Socioeconomic status	.09*	.04	.30		
Subtype/hemoglobin	-.09/.04	.15/.04	-.08/.13		
Child friendship qualities total	.01*	.00	.32		
Child subjective disease severity	.01*	.00	.25		
Caregiver Symptom Checklist-90-Revised Scale total	.01**	.00	.22		

Significance tests were computed for the unstandardized regression coefficients (*B*), overall model (*R*²), and change statistic (ΔR^2). Disease subtype was dummy coded ("HbSS" and "other").

*Significant at $p < .05$ level. **Trend at $p < .10$ level.

disease subtype and averaged hemoglobin, followed by the significant child and caregiver variables (child perceptions of friendship qualities, child subjective perceptions of disease severity, and caregiver psychological adjustment). This model accounted for almost one third of the variance in ER utilization ($R^2 = 0.31$) and was significant, $F(6, 51) = 3.77$, $p < .01$. Significance of the coefficients and size of the standardized coefficients were examined to compare relative contributions of the caregiver and child variables. Each of the variables retained unique contributions in the prediction of ER utilization, with child friendship quality having the largest unique prediction, $t(57) = 2.73$, $p < .01$, followed by child subjective perceptions of disease severity, $t(57) = 2.13$, $p < .04$, and caregiver psychological adjustment, $t(57) = 1.88$, $p = .07$.

Demographic Variables

Child age was unrelated to ER utilization in zero-order correlations ($r = 0.02$) and was therefore dropped from regression models. However, SES (maternal education) accounted for a significant portion of the variance in ER utilization when entered on the first step of the regression models, $R^2 = 0.09$, $F(1, 56) = 5.83$, $p = .02$ (Table II). The direction of the relationship indicated that relatively higher SES was predictive of more frequent ER utilization. The unique contribution of SES to the prediction of ER utilization held in the full caregiver models, $t(57) = 2.47$, $p = .02$, and child models, $t(57) = 2.58$, $p = .01$, suggesting a unique contribution of SES to the prediction of ER utilization independent of informant adjustment and the objective and subjective disease severity variables.

Objective Disease Severity Variables

The objective disease severity variables of averaged hemoglobin at baseline and disease subtype added little to the prediction of ER utilization when entered on the second step of the regression models, R^2 change = 0.01, $F(2, 54) = 0.07$, ns (Table II). Neither baseline hemoglobin nor hemoglobinopathy (disease subtype) was a significant unique predictor of ER utilization in the caregiver or child models. Thus, these objective disease severity variables overall were poor predictors of ER utilization.

Discussion

The purpose of this prospective investigation of children's ER utilization was to examine perceptions of disease severity among children and adolescents with SCD and their caregivers while controlling for disease severity and social class (i.e., parent education). In addition, adjustment of children with SCD and their caregivers was examined as these variables influenced the use of the ER. The hypotheses of the investigation were in part confirmed indicating that caregiver adjustment accounted for a unique portion of the variance beyond that accounted for by subjective perceptions of disease severity, demographic and objective biological markers of disease severity. Specifically, poorer psychological adjustment of caregivers tended to be associated with a unique proportion of the variance in the use of the ER even after controlling for demographic and objective disease severity variables. For the child model, social adjustment was predictive of ER utilization above and beyond demographic, objective, and subjective disease

severity measures. These data are consistent with the observations of Janicke and Finney (2001, 2003) that parental and child adjustment in part are associated with health care utilization patterns. Finally, in our investigation, there was a statistical trend indicating that children's subjective perceptions of disease severity accounted for a unique proportion of the variance in ER utilization beyond the demographic, objective severity, and social adjustment scores.

Contrary to intuitive belief, researchers failed to find that objective measures of disease severity traditionally employed in research with children and adolescents with SCD (i.e., disease subtype, hemoglobin levels) are predictive of ER utilization. That other psychological variables including social adjustment of the children and adjustment of caregivers as well as perceptions of disease severity are predictive of ER use provide important information to health care providers in planning health care resources for these children and their families. In addition, the data here provide tentative support for the use of psychosocial services for caregivers in attempting to mitigate health care utilization patterns (i.e., ER visits) among children and adolescents with SCD.

Of interest, researchers found that child social adjustment, specifically friendship quality, accounted for a significant percentage of the variance in children's use of the ER beyond that accounted for by objective markers of disease severity, caregiver education, and the children's chronological age. These findings are consistent with those of previous investigators suggesting a significant association between child adjustment and health care use (Bernal et al., 2000; Janicke & Finney, 2003; Lavigne et al., 1998; Riley et al., 1993). In contrast to our expectation that poorer friendship quality (a marker of poor psychosocial adjustment) would predict greater use of emergency services, our findings revealed that greater friendship quality was positively associated with ER utilization.

Although it is only conjecture, one possible explanation for this finding is that the Friendship Qualities Scale that was employed in this investigation to assess children's impressions of relationships with a best friend assesses also communication patterns in children.^{1,2} For example, the instrument contains such items as, "If I have a problem at school or at home, I can talk to my friend about it," "If there is something bothering me, I can tell my friend about it even if it is something I cannot tell to other people," and "My friend and I argue a lot," thereby tapping communication and disclosure skills. Thus, children who are able to disclose and communicate information, also are likely to communicate

health-related symptoms and hence use the ER to a greater degree than their peers who are apt to disclose and communicate less. Johnston, Steele, Herrera, and Phipps (2003) have provided data to suggest that children with chronic illnesses relative to their healthy counterparts actually perceive life events similar to their caregivers. This was attributed to that children with illnesses communicate more with their caregivers than do their normally developing peers. Clearly, additional research is warranted, particularly studies that focus on children's psychosocial adjustment, capacity to disclose both good and bad events, and communication styles that focus on disease symptoms so as to determine the influence of such factors on children's ER use. As Bukowski (personal communication, 2004) has observed, one problem and perhaps a general strength with measures of friendship is that we do not know much about what actually motivates a particular response. One frequently overlooked component of the friendship dimension is the management component. Thus, children with successful and competent friendships may also be competent in the management of their health care. As Bukowski (personal communication, 2004) has con-

¹An additional analysis was conducted that examined specific items from the Friendship Qualities Questionnaire that reflected a child's willingness to communicate. From this four-item communication subscale that was verified by means of factor analyses, regression equations were repeated and findings revealed that ER use could be predicted above and beyond objective disease severity measures and demographic data. These findings might be interpreted to support our hypotheses that higher scores on the Friendship Qualities Questionnaires predict ER utilization because children are more willing to communicate to caregivers (e.g., about pain episodes, suffering). Thus, ER use appears to be a combination of the children being willing to inform caregivers that they are in pain or suffering and the caregivers' psychological adjustment (i.e., if poorly adjusted the caregiver may overreact to the children's communication by always bringing them to the ER), perceptions that pain episodes are fairly severe and access to the ER.

²The subscales for the Friendship Qualities Scale were examined separately in individual regression analyses. Specifically, when researchers broke the scale down into its component subscales, findings revealed that the closeness subscale was the only subscale of the measure that was predictive of ER utilization, beyond that which was accounted for by SES, disease subtype, and average baseline hemoglobin values. It should be noted, however, that the closeness subscale was highly intercorrelated with other Friendship Qualities subscales (i.e., $r = 0.82$ between closeness and help subscales), ($r = 0.70$ between closeness and security), and ($r = 0.58$ between closeness and companionship). Closeness and Conflict were largely unrelated ($r = .06$). In short, while the closeness subscale appears to be the best predictor among the subscales, the subscales are so collinear that this may not really inform us of very much.

cluded children who manage friendship in an assertive way also will manage their health care in an assertive way.

Of particular interest is the finding of a trend that caregiver adjustment uniquely predicted frequency of ER visits even after controlling for children's age, parental education, hemoglobin levels, and hemoglobinopathy. Thus, in our investigation and consistent with the observations of others (Kelleher & Starfield, 1990; Riley et al., 1993; Ward & Pratt, 1996), there is a positive association of caregivers reporting less psychosocial adjustment, also making greater use of ER facilities. Although these data suggest only a trend, they are of interest and support additional replication of this investigation with most participants. The moderate effect size suggests that the trend toward significance is likely because of low power, that is, a function of the rather small sample size in this investigation.

The contribution of this investigation must be considered in light of several study limitations. First, the ranges for disease severity were rather restricted because of the characteristics of the sample. This in part may explain why objective measures of disease severity were not predictive of ER visits. Unfortunately, this is an issue characteristic of a tertiary care facility in which most patients have severe disease presentation. Second, this study employed only one index of health care utilization (i.e., ER use). For individuals with SCD, medical contact is typically made through crisis situations including the ER. It may be difficult to delineate specific measures of health care utilization (e.g., outpatient clinic visits, number of days in the hospital) because of the widespread use of the ER for the management of SCD. Thus, ER use seemed to be the most logical index of health utilization outcome for this population. Finally, the study included a relatively few participants, thereby mitigating the power of the investigation and potentially affecting the reliability of the regression models. Additional multisite studies will need to be conducted that examine several dimensions of health care utilization in children with SCD as well as other children with chronic illnesses.

Notwithstanding the aforementioned limitations, the present data provide tentative support for the notion that one dimension of health care utilization (i.e., ER use) for children with SCD may be independent of disease severity and predicted by caregivers' psychological adjustment as well as children's capacity to communicate and disclose information regarding friendships (peer adjustment). Of further interest is that subjective ratings of disease severity uniquely predicted ER use. Although clearly in need of replication, our findings are interesting and of value as they clearly provide support

for the use of psychological services in assessing those families who may be more likely to use emergency facilities, particularly caregivers who endorse problems with adjustment. Further, the data provided in this investigation also suggest that by providing psychological support services for their caregivers, this may diminish inappropriate use of ER facilities. Clinical trials are needed that examine the impact of assisting caregivers in their psychosocial adjustment difficulties on other indices of health care utilization including outpatient office visits, days in the hospital, as well as ER use. This hopefully will result in experimental validation of the longitudinal data provided in this particular investigation.

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