Examination of Risk and Resiliency in a Pediatric Sickle Cell Disease Population Using the Psychosocial Assessment Tool 2.0

Cynthia W. Karlson,1 PhD, Stacey Leist-Haynes,2 BA, Maria Smith,2 MA, Melissa A. Faith,1 MA, T. David Elkin,1,2 PhD, and Gail Megason,2 MD

1Department of Psychiatry and Human Behavior and 2Department of Pediatrics, Division of Hematology/Oncology, University of Mississippi Medical Center

All correspondence concerning this article should be addressed to Cynthia W. Karlson, PhD, University of Mississippi Medical Center, 2500 North State Street, Jackson, MS 39216, USA. E-mail: ckarlson@umc.edu

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Objective To evaluate the Psychosocial Assessment Tool 2.0 (PAT) as an appropriate screening measure of risk for patient and family psychological distress in pediatric sickle cell disease (SCD).

Methods 219 caregivers completed the PAT during regular hematology clinic visits. Confirmatory factor analysis and tests of reliability were conducted. Multilevel modeling examined change and predictors of risk scores across four assessments.

Results Confirmatory factor analysis factor loadings ranged from .03 to .81, and reliability coefficients ranged from .43 to .83. Risk for patient and sibling emotional problems, family problems, and parent stress reaction decreased over time. Increased patient age, chronic blood transfusion, lower caregiver education, caregivers being divorced, fewer adults and more children in the home, and greater financial difficulties were independent predictors of psychosocial risk.

Conclusions Results suggest that the PAT has utility in a pediatric sickle cell disease sample. Most caregivers reported low distress and high resiliency factors in this population.

Key words caregiver; longitudinal; psychosocial adjustment; risk factors; sibling; sickle cell disease.

Sickle cell disease (SCD) is a chronic and hereditary disorder found primarily in people of African, Mediterranean, and Latin American descent (Brawley et al., 2008). In the United States, it is the most common inherited blood disorder, affecting approximately 70,000–100,000 individuals, and occurs in approximately one out of every 500 African Americans (Brawley et al., 2008; National Center for Biotechnology Information, 2011). The etiology of the disease involves the distortion of red blood cells, which results in reduced oxygen delivery to tissue and disruption of healthy blood flow. When blood flow is disrupted, intense pain, infection, stroke, and organ damage can occur (Bediako, 2009). Thus, children with SCD have more frequent hospitalizations, intellectual disabilities, and poor health status compared with their African American peers without SCD (Boulet, Yanni, Creary, & Olney, 2010). Disease management most commonly consists of increased fluid intake, limiting physical activity, folic acid supplementation, analgesic and anti-inflammatory medications, and antibiotics to reduce bacterial infections (National Center for Biotechnology Information, 2011). Although bone marrow transplant may offer a cure for children with SCD, bone marrow transplant is currently available primarily to children with severe disease who have siblings with identical human leukocyte antigen (Majumdar et al., 2010). Thus, pediatric SCD is characterized by both acute and chronic disability and disease management.

Although there has been recent improvement in disease management for children with SCD (e.g., use of the antineoplastic agent hydroxyurea), formidable health disparities for racial and ethnic minority children with chronic health conditions remain (Berry, Bloom, Foley, & Palfrey, 2010; Lemanek & Ranalli, 2009). For instance, African American children with chronic asthma have higher rates of emergency department visits, hospitalizations, and...
mortality than Caucasian children with chronic asthma (Berry et al., 2010). Similarly, children with SCD report delays in accessing health care, despite higher rates of utilization (Boulet et al., 2010).

Research in other pediatric medical populations, such as cancer, burn, and transplant, has identified specific risk factors such as lower socioeconomic status (SES), low caregiver education, limited social support, and poor family functioning as risk factors associated with increased illness symptoms and psychological distress (Kahana, Freeny, Youngstrom, & Droter, 2006; Lemanek & Ranalli, 2009). These risk factors seem to parallel demographic characteristics commonly seen in African American families, placing the pediatric SCD population at particular risk for poor health-related quality of life, psychological distress, and social complications (Sue & Sue, 2008). One study found that children with SCD had significantly lower health-related quality of life compared with healthy control subjects because of both disease status and lower SES (Hijmans et al., 2010). Children and adolescents with SCD also have more difficulties with internalizing and anxiety symptoms than their peers (Brown, Eckman, Baldwin, Buchanan, & Dingle, 1995), as well as social competency and peer relationships (Barakat, Lash, Lutz, & Nicolaou, 2006). With such psychological and social complications in mind, pediatric researchers have established the need for children with chronic health conditions, particularly those of racial and ethnic minorities, to be evaluated for psychosocial risk factors (Brown et al., 1995).

Researchers have posited that in addition to health disparities, cultural bias in family assessment measures is another challenge to meet the needs of the SCD population (Mitchell, Patterson, & Boyd-Franklin, 2011). Because of this, and along with continued distrust of the medical community (Corbie-Smith, Thomas, & George, 2002), underrepresented racial and ethnic minority populations need appropriate and culturally sensitive assessment measures to meet their physical and mental health care needs (Cohen et al., 2008). In accordance with this growing emphasis, several researchers have discussed resiliency factors in addition to risk factors that are associated with the African American community (Boyd-Franklin, 2003; Caldwell-Colbert, Parks, & Eshun, 2009; Lemanek & Ranalli, 2009). Faith and spirituality, extended family networks, reciprocity (i.e., family members all contribute to the common good), and role flexibilities (e.g., a grandmother assuming the primary caregiver role) are examples of resiliency factors that appear to protect against psychosocial distress in the African American community. Thus, there is a need to incorporate these salient strengths and vulnerabilities into culturally sensitive measures for families of children with SCD.

Use of psychosocial screening measures, such as the Psychosocial Assessment Tool 2.0 (PAT; Pai et al., 2008), may be a step toward this aim. The PAT was originally normed in a majority White pediatric oncology population. However, the PAT collects information on an array of demographic, cultural (e.g., part of a faith-based community), social support, patient, sibling, caregiver, and family belief (e.g., belief in ability to cope) variables that may be particularly applicable to the pediatric SCD population, both in capturing vulnerabilities and strengths. Herein, we empirically investigated the utility, factor structure, and reliability of the PAT in a cross-sectional pediatric SCD sample. We further examined independent psychosocial risk factors of patient and family distress during the course of a year, in the context of a risk and resiliency framework (Brown et al., 2000). Based on previous research regarding risk (Berry et al., 2010; Kahana et al., 2006) and resiliency (Caldwell-Colbert et al., 2009; Lemanek & Ranalli, 2009) factors in African Americans, we hypothesized that demographic psychosocial risk factors, as well as resiliency factors, would be high in our pediatric SCD sample. We also hypothesized that patient, sibling, and caregiver psychosocial risk for distress would be similar to the normative pediatric oncology population, and that there would be little change during the course of a year (Hoff, Palermo, Schluchter, Zebracki, & Drotar, 2006), given the ongoing acute and chronic burden of SCD on children and their families.

Methods

Participants

Eligible families were identified by medical staff daily chart review. Caregivers were approached in the waiting room or an examination room before meeting with a physician. Approximately 80% of caregivers who had approached to participate in this study completed the initial assessment battery. “Not currently having time” was the most commonly cited reason for not participating. Participants at initial assessment consisted of 219 African American caregivers (mean age = 34.16 years, SD = 9.75) of children with SCD (100% African American; mean age = 7.48 years, SD = 5.56, range 2 months to 18 years; 46% female) from a university medical center that serves both rural and urban families throughout the state. Similar to other studies (Thompson et al., 1999), majority of children (70%) were diagnosed with SCD hemoglobin (Hb) SS genotype. As shown in Table I, 19% of patients were receiving chronic blood transfusions secondary to stroke,
abnormal transcranial Doppler results, recurrent splenic sequestration, and/or acute chest syndrome. Most (90%) caregivers were mothers, 5% were fathers, and 5% were other relations (e.g., grandmother, aunt, uncle, stepfather). Inclusion criteria at initial assessment consisted of being a primary caregiver of a child with SCD between 0 and 18 years. Participants were excluded if the caregiver (a) was non-English speaking or (b) had developmental delays or cognitive impairment.

Out of 219 caregivers who completed the initial assessment, 100 caregivers (46%) completed measures approximately 4 months later (T2), 78 caregivers (36%) approximately 8 months later (T3), and 77 caregivers (35%) approximately 12 months later (T4). Low retention rates were primarily due to missed, rescheduled, or infrequent clinic visits (e.g., once a year). Caregivers who completed T4 were more likely to have a child with SCD Hb SS, \( \chi^2 (1, n = 219) = 4.94, p = .03 \), and have a child receiving chronic blood transfusions, \( \chi^2 (1, n = 219) = 8.76, p = .003 \), than those who did not complete T4. Demographic and disease characteristics were similar across the four assessment periods. However, a greater portion of caregivers at T3 had children on chronic blood transfusions (33%) compared with initial assessment (19%), \( \chi^2 (1, n = 219) = 6.53, p = .01 \).

**Measures**

**Demographic Information**

The demographic information form included items regarding the child patient’s name, previous name (e.g., adoption or marriage), date of birth, gender, ethnicity, and diagnosis.

**The Psychosocial Assessment Tool 2.0**

The PAT (Pai et al., 2008) is a brief 69-item screening tool originally designed to measure psychosocial risk in families of a child newly diagnosed with cancer. Items 9 and 15i that are specific to cancer were modified to indicate “illness” for our pediatric SCD sample. Items 9 and 15i are not scored, and thus modification did not affect subscale or total PAT scores. Developed by Kazak and colleagues (Kazak et al., 2003; Pai et al., 2008), the PAT has seven subscales: Family Structure and Resources (e.g., number of adults in the home, financial difficulties, transportation), Social Support (e.g., for childcare, finances), Child Problems (patient internalizing, externalizing, and social problems), Sibling Problems (sibling internalizing, externalizing, and social problems), Family Problems (family conflict, medical problems), Parent Stress Reactions (e.g., jumpy, nightmares), and Family Beliefs (belief in family’s ability to cope and make good treatment decisions). Additional demographic information (e.g., caregiver education, part of faith-based community) is also collected. Fifty-seven of the 69 items are scored dichotomously with \( 0 = \) no risk (e.g., having two adults or more in home) and \( 1 = \) risk (e.g., having < two adults in home). No sibling(s) is scored as no risk. Risk subscale scores range from 0 to 1.00 and are calculated by dividing the total number of risk items endorsed by the total number of possible risk items in that subscale. A PAT Total score is calculated by summing subscale scores and can range from 0 to 7. A PAT Total score of < 1 is the lowest risk category (Universal Risk) and indicates few patient and/or family problems and stressors (Pai et al., 2008). A PAT Total score between 1 and 1.99 (Targeted Risk) indicates some patient and/or family problems and stressors. A PAT Total score of ≥ 2 is the highest risk category (Clinical Risk) and indicates many patient and/or family problems and stressors. Content, criterion-related, and convergent validity were established with the PAT subscales showing adequate (\( \alpha = .59 \)) to good (\( \alpha = .81 \)) reliability.

**Procedure**

This study was approved by the university Institutional Review Board. Informed consent was indicated with completion of assessment measures. Data were collected from July 2008 to November 2010. To examine change over time, and in parallel with standard medical care, caregivers completed measures during regularly scheduled clinic visits at approximately 4-month intervals up to four times during the course of a year. Caregivers took approximately...
15–20 min to complete the measures and were provided with a $10 gift card each time.

**Statistical Analysis**

Descriptive statistics, Pearson Chi-square test (categorical variables), and Analysis of Variance test (continuous variables) were used to examine differences in demographic and disease variables across the four assessment periods in SPSS 17.0. Missing data (4.13%) were imputed in LISREL 8.7 (Jöreskog & Sörbom, 1996), using estimated means and five iterations. A confirmatory factor analysis (CFA) was conducted in LISREL 8.7, using maximum likelihood standardized estimation factor extraction procedures and kaiser weights. The root mean square error of approximation (RMSEA) was used to examine PAT structure where values < .05 constitute good model fit, values ranged .05–.08 constitute acceptable model fit, values ranged .08–.10 constitute marginal model fit, and values > .10 constitute poor model fit. In addition, the non-normed fit index (NNFI), comparative fit index (CFI), and standardized root mean square residual (SRMR) were used to assess model fit. Internal consistency was examined using Cronbach’s alpha coefficients. Analyses of within-subject changes over time were conducted in LISREL 8.7, using multilevel modeling (Tabachnick & Fidell, 2007). Multilevel modeling analyses used full information maximum likelihood estimation to handle missing longitudinal data and improve parameter estimates for the unbalanced design (Goldstein, 1986; Longford, 1987). In this case, up to four assessments were nested within 219 caregiver participants. Level 1 variables were those measured on a repeated basis (i.e., PAT measure). Variables that were measured once (e.g., child gender) contained only between person variance and were modeled as Level 2 variables. A significance threshold of \(p < .05\) was used throughout analyses.

**Results**

**Descriptive Statistics**

Table I presents demographic information across the four assessment periods. At initial assessment, 59 (27%) caregivers were married, 143 (65%) were single, and 12 (6%) were divorced or widowed. Thirty (14%) of caregivers had less than a high school education, 86 (39%) had a high school or general equivalence diploma, and 103 (47%) had some college/vocational classes or higher. For transportation to appointments, 142 (65%) caregivers had their own car, whereas 53 (24%) used Medicaid/Medicare transportation.

**Confirmatory Factor Analysis**

We first examined the factor structure of the PAT at initial assessment. We hypothesized that the original seven-factor structure of the PAT would be the strongest model in this population. The model demonstrated acceptable model fit \((RMSEA = .05, CI = .05–.06; NNFI = .77, CFI = .78, SRMR = .07)\). Factor structure, Chronbach’s alphas, and standardized factor loadings are summarized in Figure 1. For factors 2 through 7, the majority of items loaded on the factor from which they were derived (range: .15–.81). However, only four of eight items loaded on the Family Structure and Resources factor. PAT subscale alphas ranged from .43 to .83 and PAT Total \(\alpha = .84\), indicating poor to good internal consistency. As seen in Table II, the majority of PAT scales were significantly correlated with each other at initial assessment.

In an attempt to improve model fit and subscale reliability, we created alternative item and subscale scores based on raw ordinal data available for the Social Support, Parent Stress Reaction, and Family Beliefs subscales. Using ordinal data in statistical modeling as compared with dichotomized variables improves power and parameter estimates (Tabachnick & Fidell, 2007). We further removed the Family Structure and Resources subscale, item 12p (victim of violence) on the Sibling Problems subscale, and item 13b (substance use caused problems) on the Family Problems subscale because of loadings of < .20. This improved the CFA solution \((\Delta \chi^2 = 780.02, \ p < .001)\) with 47 items making up six subscales \((RMSEA = .06; CI = .05–.06; NNFI = .83; CFI = .84; SRMR = .07)\). Item loadings ranged from .26 to .89. Use of this alternative model improved internal consistency for the Social Support \((\alpha = .90)\), Parent Stress Reaction \((\alpha = .72)\), and Family Beliefs \((\alpha = .62)\) subscales but reduced the PAT Total scale reliability \((\alpha = .69)\). To address the hypotheses of this study and compare our results with the normative PAT pediatric oncology population, original dichotomized risk scores were used in subsequent analyses. Items from the Family Structure and Resources and Family Beliefs subscales were used primarily for descriptive purposes because of poor factor structure and poor reliability.

**PAT Scales**

At initial assessment, total PAT mean was 1.12 (SD = 0.74; range: 0–4.31) with 109 caregivers (50%) scoring in the Universal Risk range, 80 (36%) in the Targeted Risk range, and 30 (14%) in the Clinical Risk range. As seen in Table III, caregivers generally reported low risk for psychosocial problems on the PAT. At initial assessment, psychosocial risk scores were highest for the Family Structure and...
Figure 1. Summarized risk score factor loadings at initial assessment. Struc/Res = Structure and Resources; Parent Stress = Parent Stress Reaction; Ed = Highest education completed.

Table II. Zero-Order Correlations Between PAT Scales at Initial Assessment

<table>
<thead>
<tr>
<th></th>
<th>Family structure/resources</th>
<th>Social support</th>
<th>Child problems</th>
<th>Sibling problems</th>
<th>Family problems</th>
<th>Parent stress reaction</th>
<th>Family beliefs</th>
<th>PAT total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family structure/resources</td>
<td>–</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>.22**</td>
<td>–</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child problems</td>
<td>.14*</td>
<td>.15*</td>
<td>–</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling problems</td>
<td>.17*</td>
<td>.07</td>
<td>.41**</td>
<td>–</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family problems</td>
<td>.15*</td>
<td>.18**</td>
<td>.32**</td>
<td>.36**</td>
<td>.36**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent stress reaction</td>
<td>.16*</td>
<td>.14*</td>
<td>.15*</td>
<td>.16*</td>
<td>.15*</td>
<td>–</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family beliefs</td>
<td>.11</td>
<td>.21**</td>
<td>.15*</td>
<td>.10</td>
<td>.22**</td>
<td>.20**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAT total</td>
<td>.43**</td>
<td>.35**</td>
<td>.60**</td>
<td>.55**</td>
<td>.38**</td>
<td>.36**</td>
<td>.35**</td>
<td></td>
</tr>
</tbody>
</table>

Note. *p < .05. **p < .01.
Resources and Child Problems subscales. Most caregivers reported some social support and believed that their family could cope with their child’s SCD, as well as make good treatment decisions.

### Longitudinal Regression Analyses

#### Social Support

PAT risk for low social support did not significantly change over time ($B = -0.003$, $z = -0.47$, $p = .64$). Across assessment periods, fewer adults in the home ($B = -0.04$, $z = -2.61$, $p = .01$) and increased financial difficulties ($B = 0.03$, $z = 2.65$, $p = .01$) were associated with increased risk for low social support.

#### Child Problems

PAT risk for child emotional problems (e.g., mood changes, worry) marginally decreased over time ($B = -0.02$, $z = -1.88$, $p = .06$), whereas behavioral problems (e.g., easily distracted, have difficulty with friends) did not change over time ($z = -1.51$, $p = .13$). Across the four assessment periods, older children had increased risk for emotional problems ($B = 0.01$, $z = 2.77$, $p = .01$) and children with a caregiver with lower education had increased risk for both emotional and behavior problems ($B = -0.02$, $z = -2.48$, $p = .01$).

#### Sibling Problems

PAT risk for sibling emotional problems significantly decreased over time ($B = -0.02$, $z = -2.27$, $p = .02$), but sibling behavior problems did not change ($z = -1.33$, $p = .18$). Across the four assessment periods, increased risk for sibling emotional and behavioral problems was associated with more children in the home ($B = 0.02$, $z = 3.42$, $p < .001$) and greater financial difficulties ($B = 0.02$, $z = 2.03$, $p = .04$).

### Caregiver Subscales

PAT risk for both family problems ($B = -0.02$, $z = -3.40$, $p < .001$) and parent stress reaction ($B = -0.02$, $z = -2.47$, $p = .01$) significantly decreased over time. Across the four assessment periods, increased risk for family problems was associated with children receiving chronic blood transfusions ($B = 0.05$, $z = 2.13$, $p = .03$), caregivers being divorced as compared with married/partnered, $t(165) = 2.38$, $p = .01$, or single, $t(322) = 3.68$, $p < .001$, and increased financial difficulties ($B = 0.03$, $z = 3.78$, $p < .001$). Increased risk for parent stress reaction was also associated with several demographic variables, including children not having Medicaid insurance ($B = -0.09$, $z = -2.87$, $p = .004$), lower caregiver education ($B = -0.02$, $z = -1.98$, $p < .05$), more children in the home ($B = 0.02$, $z = 2.24$, $p = .02$), and greater financial difficulties ($B = 0.02$, $z = 2.29$, $p = .02$).

### PAT Total Risk

PAT total risk score ($B = -0.06$, $z = -2.93$, $p = .003$) and risk category ($B = -0.05$, $z = -2.17$, $p = .03$) showed significant reductions over time. Within the three risk categories, those families initially classified as Universal Risk ($B = 0.01$, $z = 0.73$, $p = .46$) generally reported no significant change in total psychosocial risk over time, whereas families classified as Targeted Risk ($B = -0.09$, $z = -3.75$, $p < .001$) and Clinical Risk ($B = -0.28$, $z = -4.47$, $p < .001$) reported significant reductions in total psychosocial risk over time. Specifically, eight (24%) of the 35 families who completed T4 and were initially in the Universal Risk category changed to the Targeted Risk category at T4. Of the 42 families who completed T4 and were initially in the Targeted or Clinical Risk categories, 23 (55%) changed to a lower risk category, whereas 19 (45%) stayed the same or changed to a higher risk category at T4. Lower caregiver education ($B = -0.09$, $z = -3.34$, $p = .001$), fewer adults in the home ($B = -0.12$, $z = -2.75$, $p = .01$), more children in the home ($B = 0.07$, $z = 2.96$, $p = .003$), and greater

### Table III. PAT Scale Score Means and Standard Deviations Across Assessment Periods

<table>
<thead>
<tr>
<th></th>
<th>Initial assessment</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[n = 219 M (SD)]</td>
<td>[n = 100 M (SD)]</td>
<td>[n = 78 M (SD)]</td>
<td>[n = 77 M (SD)]</td>
</tr>
<tr>
<td>Family structure/resources</td>
<td>.26 (0.12)</td>
<td>.27 (0.12)</td>
<td>.25 (0.13)</td>
<td>.24 (0.11)</td>
</tr>
<tr>
<td>Social support</td>
<td>.09 (0.23)</td>
<td>.11 (0.25)</td>
<td>.10 (0.24)</td>
<td>.10 (0.23)</td>
</tr>
<tr>
<td>Child problems</td>
<td>.25 (0.21)</td>
<td>.19 (0.18)</td>
<td>.23 (0.24)</td>
<td>.24 (0.22)</td>
</tr>
<tr>
<td>Sibling problems</td>
<td>.11 (0.17)</td>
<td>.08 (0.17)</td>
<td>.08 (0.16)</td>
<td>.09 (0.15)</td>
</tr>
<tr>
<td>Family problems</td>
<td>.13 (0.16)</td>
<td>.10 (0.14)</td>
<td>.10 (0.16)</td>
<td>.10 (0.14)</td>
</tr>
<tr>
<td>Parent stress reaction</td>
<td>.11 (0.24)</td>
<td>.09 (0.19)</td>
<td>.05 (0.14)</td>
<td>.06 (0.17)</td>
</tr>
<tr>
<td>Family beliefs</td>
<td>.16 (0.22)</td>
<td>.17 (0.23)</td>
<td>.14 (0.22)</td>
<td>.19 (0.25)</td>
</tr>
<tr>
<td>PAT total</td>
<td>1.12 (0.74)</td>
<td>1.00 (0.70)</td>
<td>.95 (0.70)</td>
<td>1.03 (0.64)</td>
</tr>
</tbody>
</table>
financial difficulties ($B = 0.17$, $z = 5.46$, $p < .001$) were all related to increased total psychosocial risk across assessment periods.

**Discussion**

This study assessed the psychometric properties of the PAT in a clinical pediatric SCD sample. We also evaluated the utility of the PAT as a screening measure for psychosocial risk and the extent to which psychosocial risk changed during the course of a year in this sample. The Society of Pediatric Psychology has recommended that psychological measures be systematically evaluated to determine applicability to racial and ethnic populations (Barakat & Alderfer, 2011; Cohen et al., 2008). This study provides a step toward that goal. Furthermore, this study adds to our understanding of longitudinal risk factors in pediatric SCD and provides clinical implications for improving care for these children and their families.

PAT risk classifications for our pediatric SCD sample (50% Universal, 36% Targeted, and 14% Clinical) were similar to those found in Pai and colleagues’ (2008) pediatric oncology sample (55% Universal, 32% Targeted, and 13% Clinical). In addition, the original seven-factor solution for the PAT was partially supported in this sample. Most subscales demonstrated adequate to good factor structure. However, the Family Structure and Resources subscale demonstrated poor factor structure and poor internal reliability. Differences in family structure observed in pediatric SCD samples (e.g., mothers more likely to be single or never married; Thompson et al., 1999) compared with other pediatric medical samples (Pai et al., 2008; Pai, Tackett, Ittenbach, & Goebel, 2012) may help explain this finding and highlight cultural differences in the pediatric SCD population. The Family Beliefs subscale also demonstrated less than adequate internal consistency in our sample, which is consistent with research on the PAT in pediatric kidney transplant patients (Pai et al., 2012). To address these reliability concerns, we tested an alternative model using only six factors and raw ordinal scores. This alternative model improved overall model fit and subscale reliabilities; however, further research is needed to determine whether this alternative PAT scoring method provides consistently improved psychometrics in other pediatric SCD samples.

Although longitudinal results must be interpreted with caution because of low retention rates, similar demographic and disease characteristics across the four assessment periods allows us to draw some tentative conclusions. In our sample, we found that risk for child and sibling emotional problems, family problems, and parent stress reaction tended to decrease during the course of a year. A reduction in PAT Total risk score over time was also observed for those families initially in the Targeted and Clinical Risk categories. It should be noted, however, that a portion of families in the Targeted and Clinical Risk categories either reported no change or more psychosocial stressors at the end of a year. Thus, although psychosocial stressors tend to decrease over time for many families of children with SCD, concerns may not spontaneously resolve for all families. In this manner, the PAT may be a valuable screening tool for health care professionals to monitor families of children with SCD and direct comprehensive interventions, such as social work services, individual cognitive-behavioral therapy, interpersonal therapy, or family therapy to address concerns (Gold, Treadwell, Weissman, & Vichinsky, 2011; Barakat, Schwartz, Salamon, & Radcliffe, 2010).

Consistent with other research in pediatric medical populations (Gil et al., 2000; Barakat et al., 2006; Kazak, Rourke, & Crump, 2003), we found that older child age, lower caregiver education, caregivers being divorced, fewer adults and more children in the home, and financial difficulties placed SCD families at greater risk for psychosocial distress. The observed increased risk for older children to experience emotional problems may be related to increased responsibility for health care management faced by adolescents with SCD (Oliver-Carpenter, Barach, Crosby, Valenzuela, & Mitchell, 2011), or may be related to normal challenges faced during the transition from adolescence to early adulthood (Smetana, Campione-Barr, & Metzger, 2006). With regard to sibling problems, caregivers with financial difficulties may have fewer resources available to assist siblings in coping with a patient’s SCD diagnosis, treatment, and impact on the family. This may further be compounded when there are more children in the home, leaving siblings at increased risk for negative emotions and behaviors (Brody, Stoneman, & Burke, 1987). Interestingly, it appears in our sample that caregivers being divorced may be a greater risk factor for family problems than being single, perhaps because of changes in financial resources and family structure that occur with divorce (Adam & Chase-Lansdale, 2002; Varner & Mandara, 2009). Regarding disease and medical characteristics, a child receiving chronic blood transfusions was associated with increased risk for family problems, suggesting that greater illness severity and high treatment demand puts an additional strain on families of children with SCD. A child not having Medicaid insurance was also related to increased risk for parent stress reaction, which may be due to the high annual cost of pediatric SCD and...
potential burden of medical expenses on families of children who do not have Medicaid coverage (Mvundura, Amendah, Kavanagh, Sprinz, & Grosse, 2009).

Although identifying and discussing risk factors for psychosocial problems in children with SCD is important, it is also important to note that the majority of families in our population had low-risk scores across problem subscales. Moreover, the majority of caregivers indicated that they believed their family could cope with SCD and that their family and physicians would make good treatment decisions. These findings might be explained by the fact that almost 90% of our population reported being involved in a faith-based community, which is a protective factor against psychological distress in African Americans (e.g., Caldwell-Colbert et al., 2009). Such findings are also consistent with other researchers’ observations that many African Americans exhibit significant psychosocial strengths and resiliency, despite continued physical and mental health disparities (Boyd-Franklin, 2003; Brown et al., 2000; Lemanek & Ranalli, 2009). Thus, it appears that faith in their families, physicians, and spiritual community aids families in coping with SCD. More research on these and other protective factors is needed to promote positive physical and mental health outcomes in pediatric SCD populations.

This study has several strengths as well as limitations. To our knowledge, ours is the first study to assess the applicability of the PAT in a pediatric SCD sample. To this end, the PAT appears to be a valuable screening tool for identifying families of children with SCD in need of support, although modification of scoring may be warranted to increase subscale reliabilities. Another strength is our high initial response rate (approximately 80%) which increases generalizability of our findings to the broader SCD population. While we obtained a large initial sample of caregivers, demographic information is not available for those families who refused to participate thereby introducing the potential for participation bias. In addition, our study had a low retention rate that was influenced by disease status (i.e., SCD Hb SS genotype and receiving chronic blood transfusions), which may have biased longitudinal results. Further, given the number of scored PAT items (57 items), CFA analyses were somewhat under-powered from the recommended five cases per parameter estimate. These sample limitations are similar to other pediatric SCD studies and speak to the continued need for research investigating cultural perceptions and perceived barriers surrounding engagement in research (Barakat et al., 2010). Other study limitations include the cross-sectional design and parent-only report of child and family functioning. Future studies would benefit from examining longitudinal psychosocial risk factors using a prospective cohort design to control for different phases of disease course and treatment, as well as multiple informants and additional measures to examine convergent and content validity of the PAT in pediatric SCD families.

In sum, results of this study indicate that the PAT may be a promising screening tool for evaluating psychosocial risk in children and families affected by SCD. We found that risk for psychosocial problems tended to decrease during the course of a year in children with SCD and their families. Across time, particular demographic and disease characteristics such as older child age, receiving chronic blood transfusions, lower caregiver education, caregivers begin divorced, fewer adults and more children in the home, and more financial difficulties were associated with increased risk for psychosocial problems. Preventative efforts targeting families with more risk factors and providing early intervention appears warranted.

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References


