

Psychometric Properties of the Psychosocial Assessment Tool-General in Adolescents and Young Adults With Sickle Cell Disease

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The data were collected as part of a larger longitudinal study (Crosby et al., 2013; Crosby, Joffe, Kalinyak, Bruck, & Joiner, 2013) but data from the current study has not been reported in any published manuscripts.

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Abstract

Objectives Adolescents and young adults (AYAs) with sickle cell disease (SCD) experience psychosocial factors that increase their risk for poor disease management and health outcomes. Routine assessment of psychosocial factors that perpetuate health disparities is recommended. The Psychosocial Assessment Tool 2.0_General (PAT2.0_GEN) AYA is a psychosocial screener with potential clinical utility in AYAs with SCD. This article is a preliminary examination of the internal consistency and predictive validity of this measure in a sample of 45 AYAs with SCD. **Methods** Participants completed the PAT2.0_GEN AYA, Pediatric Quality of Life Inventory, and a demographics form; psychosocial referral data were also collected. **Results** Internal consistency for the PAT2.0_GEN AYA was acceptable except for the Family Beliefs (0.67) and Structure and Resources subscales (0.37). PAT2.0_GEN AYA scores were associated with an increased likelihood of referral for intervention within 4 months. **Conclusions** The PAT2.0_GEN AYA holds promise as a screener to identify psychosocial risk factors that may compromise health outcomes in AYAs with SCD.

Key words: chronic illness; family; pediatric; psychosocial risk; quality of life; screening.

Over the past few decades, advances in the treatment of sickle cell disease (SCD) have resulted in increased life expectancy (Hamideh & Alvarez, 2013; Hassell, 2010; Lanzkron, Carroll, & Haywood, 2013; Yanni, Grosse, Yang, & Olney, 2009). Subsequently, SCD-related morbidity and mortality has shifted to adolescence and young adulthood when the disease worsens and complications including acute pain episodes, chronic pain due to organ or bone damage, pulmonary hypertension, renal and cardiac dysfunction, and

stroke accelerate (Ballas et al., 2010, 2012; Quinn, Rogers, McCavit, & Buchanan, 2010; Vichinsky et al., 2010). Approximately 11% of adolescents and young adults (AYAs) with the most severe genotype (hemoglobin SS) will experience an overt stroke (Wang, 2007) and 37% of patients aged ≥ 14 years, across genotypes, will have a silent stroke (no obvious symptoms but detectable with imaging; Bernaudin et al., 2011). The risk of stroke increases into adulthood but the risk for neurocognitive deficits in general

is even greater. Approximately 50% of adults with SCD with no documented history of stroke have neurocognitive limitations (Bernaudin et al., 2011; DeBaun et al., 2012; Kugler et al., 1993; Ohene-Frempong et al., 1998). This disease progression experienced during adolescence and young adulthood necessitates a high level of disease self-management.

Psychosocial factors place AYAs with SCD at risk for difficulties with disease management. A disproportionate number of persons with SCD are ethnic minorities (DeBaun & Telfair, 2012). In the United States, SCD is found primarily in African Americans (1 in every 365 live births) and Hispanic/Latino Americans (1 in every 1,000–1,400 live births) (Hassell, 2010; US National Library of Medicine, 2012). In addition, children with SCD tend to have parents with low levels of educational attainment and low incomes (Boulet, Yanni, Creary, & Olney, 2010). The National Health Interview Survey Child Sample Core found that families of children with SCD were significantly more likely than their counterparts (African American families of children without SCD) to report lower levels of parental education and household incomes <100% of the federal poverty level (Boulet et al., 2010).

These racial/ethnic and income disparities may contribute to difficulties in accessing health care, the quality of care received and health care utilization (Berry, Bloom, Foley, & Palfrey, 2010; Conroy, Sandel, & Zuckerman, 2010; Lemanek & Ranalli, 2009; Agency for Healthcare Research and Quality, 2010). Approximately 10% of families of children with SCD in the National Health Interview Survey Study reported that they had difficulty accessing care (i.e., reaching providers by phone, obtaining an appointment in a timely manner, long wait times at visits) and 6% reported problems affording prescriptions (Boulet et al., 2010). Given their racial and ethnic background, individuals with SCD, especially AYAs, are more likely to experience discrimination in the health care system particularly around treatment for pain (Lattimer et al., 2010; Zempsky, 2009). Because AYAs' SCD pain has been treated with opioid medications since childhood, they often learn which medications and dosages are effective in managing their pain. Providers unfamiliar with SCD may misinterpret this knowledge as drug-seeking behavior and may develop negative attitudes toward patients (Lattimer et al., 2010). These attitudes often contribute to high rates of nonadherence and acute health care utilization (Elander, Beach, & Haywood, 2011; Lattimer et al., 2010; Zempsky, 2009). A recent study by Haywood et al. (2014) found that SCD patients reporting discrimination associated with health-related stigma were 53% more likely to report being nonadherent to treatment (Haywood et al., 2014). Yusuf, Atrash,

Grosse, Parker, and Grant (2010) found that AYAs with SCD were less likely to seek preventative care than other age-groups of patients with SCD. In the absence of a regular care provider, AYAs may use acute care settings more often (e.g., emergency room [ER]). Data indicate that AYAs have higher rates of ER visits (3.61 per patient per year vs. 2.59 per patient per year) than other age-groups of patients with SCD (Yusuf et al., 2010).

In view of the significant influence of psychosocial factors on SCD disease management and outcomes, timely assessment and treatment of psychosocial issues is recommended, particularly in AYA populations, given their additional developmental risks. National Heart, Lung, and Blood Institute (NHLBI) guidelines for the evidence-based management of SCD recommend routine assessment of psychosocial factors as one component of comprehensive care (Yawn et al., 2014). However, no details are provided about measures to assess these factors. The Psychosocial Assessment Tool 2.0_General (PAT2.0_GEN; Karlson et al., 2012; Pai et al., 2014; Pai, Tackett, Ittenbach, & Goebel, 2012) is a brief, standardized measure that assesses psychosocial risk in the context of pediatric chronic illness. The PAT2.0_GEN was adapted for use with general pediatric populations from the PAT2.0 developed for a pediatric oncology population (Pai et al., 2008). Based on the Pediatric Psychosocial Preventative Health (PPPH) model, this screener assesses a range of patient and family factors such as structural, financial, and family issues (Kazak, 2006). The PPPH model may be particularly well-suited for conceptualizing psychosocial risk in a diverse population like SCD because of its compatibility with a socioecological approach (Karlson et al., 2012). The model espouses that individual (e.g., psychological functioning), family (e.g., parent psychological functioning), social (e.g., peer support), and economic factors (e.g., transportation difficulties) influence disease management (Kazak, 2006).

The PAT2.0_GEN could be used for routine assessment of psychosocial risk factors in AYAs with SCD. Because the PAT2.0_GEN only takes 10–15 min to complete, AYAs could complete it during routine clinic visits. The PAT2.0_GEN has been validated among multiple pediatric populations, including youth with cancer (Kazak et al., 2011, 2012; McCarthy et al., 2009; Pai et al., 2008), inflammatory bowel disease (Pai et al., 2014), pediatric recipients of kidney transplant (Pai et al., 2012), and pediatric patients with SCD (Karlson et al., 2012). However, its validity in AYAs with SCD has yet to be determined: the mean age for children in the SCD sample was 7.48 years (Karlson et al., 2012). The PAT2.0_GEN has also not been evaluated for its utility as a patient-reported measure; caregivers complete the PAT2.0_GEN. Because

AYAs with SCD often come to clinic alone, an AYA report version is practical and would help to ensure that the data collected on AYAs living independently reflect their current situation and not that of their parent/caregiver.

The purpose of this article is to provide preliminary data on the internal consistency and predictive validity of the PAT2.0_GEN AYA report version in a sample of AYA 16–24 years of age with SCD. First, we examined the internal consistency of the PAT2.0_GEN AYA version. Given that the internal consistency for the PAT2.0_GEN has been ≥ 0.70 (except for items comprising the Family Beliefs and Structure and Resources subscales) in pediatric populations from diverse racial, ethnic, and socioeconomic backgrounds (kidney transplant, cancer, SCD), it was hypothesized that the internal consistency for the PAT2.0_GEN AYA would be in the same range (≥ 0.60) for AYAs with SCD. Second, we explored convergent validity with the Pediatric Quality of Life Inventory (PedsQL) Generic Core scales. AYAs with SCD with more psychosocial distress (e.g., AYA internalizing symptoms, disease-related parenting stress) have lower health-related quality of life (Barakat, Patterson, Daniel, & Dampier, 2008); therefore, if PAT2.0_GEN AYA scores were negatively correlated with quality of life in a sample of AYAs with SCD, it would provide preliminary support for the convergent validity of the PAT2.0_GEN AYA. Thus, we hypothesized that the PAT2.0_GEN AYA total score would be negatively associated with the PedsQL total score. Third, we assessed predictive validity examining the association between the PAT2.0_GEN AYA total score and subsequent referral for psychological or social support. Karlson et al. (2012) found that approximately 50% of families experienced some psychosocial risk and would benefit from follow-up (36% in the targeted category, and 14% in the clinical category). Therefore, we hypothesized that the PAT2.0_GEN AYA total scores would be significantly associated with the likelihood of a referral for psychosocial intervention.

Methods

Participants

Participants were AYA patients receiving care at a SCD clinic at a large Midwestern children's hospital or adult hospital. All participants in the current study were enrolled in a larger longitudinal study examining two self-management interventions for AYA patients with SCD (Crosby, Hudepohl, et al., 2013; Crosby, Joffe, Kalinyak, Bruck, & Joiner, 2013). Data from the baseline assessment for the first 45 participants enrolled in the study (from October 2011 and March 2014) who had completed the 6-month follow-up visit are reported here. Approximately 105 patients met

eligibility criteria for the larger study: (1) primary diagnosis of SCD, (2) between 16 and 24 years of age, and (3) no significant cognitive limitations based on medical chart review and physician report.

Procedures

Eligible patients were recruited via letter, phone call, or in-person in clinic or at SCD-related events. Trained research coordinators reviewed the consent form with participants and/or caregivers. To ensure understanding of the study, its procedures, and the right to withdraw, participants answered questions before providing written consent/assent (participants aged ≥ 11 years). Participants completed a variety of measures at baseline, post-intervention, and follow-up (3, 6, and 12 months after the intervention), including the PAT2.0_GEN AYA, the PedsQL, and the demographics form. Data reported here are from the baseline assessment for which participants received \$35 compensation. Self-report data were collected electronically at study visits and saved directly into a password-protected, Health Insurance Portability and Accountability Act (HIPAA)-compliant secure database. Specifically, study participants completed measures using a laptop computer with mouse or iPad with stylus. Clinical data (i.e., genotype, ER visits, hospitalizations, referrals) were abstracted from the institution's electronic medical record (EMR). The study was approved by the institutional review board.

Measures

Demographic Information

Participants completed a demographics form used in prior studies (Crosby et al., 2009, 2012) that assessed the following: sex, age, race/ethnicity, number of pain days, highest grade completed, and income level. Demographic data were also collected from the EMR: genotype, ER visits, hospitalizations, insurance type (private vs. public), and referrals for psychological or social services. We adapted our operational definition of psychological and social work intervention from Pai et al. (2012: p. 95) "being referred to or seeing an individual mental health professional for therapy or counseling to treat psychological distress" or a social problem (transportation, housing, school, financial problem) within a 4-month period following completion of the PAT2.0_GEN. Two raters (L.C., E.M.) independently reviewed participant medical records and abstracted data on referrals with interrater reliability quantified by Cohen's Kappa = .91.

Pediatric Quality of Life InventoryTM

The PedsQL Generic Core is a quality-of-life instrument designed for youth with acute or chronic health conditions (Varni, Seid, & Kurtin, 2001). It is a

23-item measure consisting of four subscales: Physical, Emotional, Social, and School Functioning. The PedsQL yields three summary scores: psychosocial health, physical health, and the total scale. Adolescents completed the Teen Report version and participants ≥ 18 years of age completed the Young Adult version. Higher scores indicate better health-related quality of life. Respondents are asked to rate each statement on a five-choice response format ranging from “0” (*Never*) to “4” (*Almost Always*). Previous studies have reported good internal consistencies for the items comprising the subscales, summary, and total scale scores of the PedsQL in Pediatric SCD (Panepinto & Bonner, 2012). Internal consistency for the current sample was 0.92 (see Table 2).

PAT2.0_GEN AYA Report Version

In the current study, AYA participants completed the PAT2.0_GEN AYA report. Consistent with the original PAT2.0, the PAT2.0_GEN AYA consists of 69 items and has five subscales: Family Structure and Resources (eight items), Family Social Support (four items), Family Problems (eight items), Parent Stress Reactions (three items), and Child Problems and Sibling Problems (30 items). A total score (with a potential range of 0–7) and seven subscale scores (with a potential range of 0–1) were calculated according to scoring described in the PAT2.0_GEN Scoring Manual (Kazak, 2011). The following cutoffs categorize family psychosocial risk scores: (a) Scores < 1 fall in the universal risk category. Families that score in the universal category tend to be resilient and have multiple psychosocial resources. As a result, these families may experience transient distress in response to the challenges of a chronic disease like SCD. In most pediatric chronic illness populations, the majority of families will score in the universal category (Kazak et al., 2007); however, it is unknown if this pattern holds for AYAs with SCD. (b) Scores between 1 and 2 fall in the targeted category. Families that score in the targeted category are typically experiencing acute psychosocial distress in response to the illnesses and have some risk factors (Pai et al., 2012, 2014). (c) Scores > 2 are considered to fall in the clinical risk category. A small number of families tend to score in the clinical risk category. These families are typically experiencing high levels of distress and multiple psychosocial risk factors (Pai et al., 2012, 2014). Examples of item content and scoring for the PAT2.0 can be found in Pai et al. (2014).

Adaptation of the PAT 2.0_GEN AYA was completed based on a literature review to examine the relevance of the original content to AYAs with SCD. Based on this review, we concluded that the all items were applicable except the following: Items 9 (“Does your child know that he/she has cancer?”), 15g

(“People will pull away from us”), and 15i (“Cancer is a death sentence”). In addition, AYAs were instructed to complete the measure in reference to himself or herself as the patient or child and to answer other questions with respect to their family (e.g., primary parent’s highest level of education, parent’s relationship status). The PAT2.0_GEN has demonstrated high reliability (0.81 for the total score and 0.62–0.81 for the subscales; Kazak, 2011), good convergent and predictive validity, and has been validated with several chronic disease populations (Karlson et al., 2012; Kazak et al., 2011; McCarthy et al., 2009; Pai et al., 2008, 2012, 2014). Reliability for the PAT2.0_GEN AYA in the current sample was 0.92 for the items comprising the total score and ranged from 0.37 to 0.95 for the items comprising the subscales.

Data Analysis

For all participants, the following de-identified data were extracted and imported into an SPSS database: demographic data, PAT2.0_GEN total score and subscale scores, PedsQL total score and subscale scores, and EMR data. Data were then coded (e.g., public vs. private insurance), cleaned (e.g., assessed for incorrect entries), and analyzed using MPlus Version 7.3 statistical analysis software (Muthén & Muthén, 1998–2012). This was a complete data set with no missing data.

Traditional descriptive statistics were used to summarize sample characteristics including participant demographics, the average number of pain days, ER visits, and hospitalizations in the 12 months before data collection, and PAT2.0_GEN AYA and PedsQL total and subscale scores. To evaluate internal consistency, Kuder–Richardson Formula 20 (KR-20) coefficients were computed for the PAT2.0_GEN AYA items. Construct validity was also examined by conducting a confirmatory factor analysis (CFA) using the PAT2.0_GEN AYA items. Pearson correlations were computed to assess convergent validity between the PAT2.0_GEN AYA and the PedsQL. Predictive validity was assessed via logistic regression odds ratios obtained by using both the PAT2.0_GEN AYA observed total score and the latent factor scores that resulted from the construct validity CFA analysis, as separate predictors of whether ($=1$) or not ($=0$) the patient was referred for psychological or social work intervention within a 4-month period after completing the measure. This period was selected because participants had clinic visits every 1–3 months.

Results

Participant Characteristics and Descriptive Statistics

Forty-five AYA patients with SCD participated in the study. The sample was primarily composed of African

Table I. Demographics and Disease Information for Study Sample ($n = 45$)

Variable	Frequency (%)	Mean (SD)
Gender (female)	30 (66.7)	
Ethnicity (African American)	45 (100.0)	
Two caregiver house	18 (40.0)	
Patient's highest grade completed		
Less than high school	17 (37.8)	
High school or General Educational Development (GED)	15 (33.3)	
Some college/vocational school	9 (20.0)	
Graduated college/vocational school	3 (6.7)	
Some postgraduate education	1 (2.2)	
Family income level		\$10,000–\$13,000
Hemoglobin genotype		
SS	33 (73.3)	
SC	10 (22.2)	
Other	2 (4.4)	
Number of pain days		77.1 (126.6)
ER visits		5.8 (15.8)
Hospitalizations		4.3 (3.0)
Psychological services or referral	20 (44.4)	
Insurance type (public)	30 (66.7)	

American females with a mean age of 18.9 years ($SD = 3.7$). See Table 1 for full demographic information. These patient characteristics are consistent with other studies in pediatric SCD populations (Guite, Logan, McCue, Sherry, & Rose, 2009; Logan & Scharff, 2005; Logan, Simons, & Carpino, 2012). The majority of patients had public insurance (66.7%) while the remaining had private or private and public insurance (20%) or no insurance coverage (13.3%), suggesting that most patients had lower socioeconomic status. The sample is also consistent with those reported in other pediatric SCD studies with respect to number of pain days, hospitalizations, and ER visits (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010). Hemoglobin SS and SC (95.5%) were the most common genotypes (see Table 1).

Internal Consistency

Internal consistency for the PAT2.0_GEN AYA was high ($\alpha = .92$; see Table 2 for PAT2.0_GEN AYA and PedsQL total scores and subscales). All subscales had KR-20 coefficients >0.70 except the Structure and Resources and the Family Beliefs subscales. The KR-20 coefficient for the Family Belief subscale was 0.67 and the KR-20 coefficient for the Structure and Resources subscale was 0.37, suggesting a lack of item content similarity, a high degree of variation in responses across items comprising these subscales, or both. Further, with respect to construct validity, results showed the seven-factor CFA (structure and resources, social support, child problems, sibling problems, family problems, stress reaction, and family beliefs) fit

Table II. Descriptive Statistics and Internal Consistency for PAT2.0_GEN AYA Total Scores and Subscales and PedsQL Total and Summary Scores

Scale	Range	M	SD	Internal consistency
PAT2.0_GEN AYA				
Total	0.19–5.03	1.35	0.97	.92
Structure/Resources (1b-d, f, education, 5, 7, 8)	0.13–0.75	0.34	0.17	.37
Social Support (4a-d)	0–1	0.18	0.32	.85
Child Problems (11a-n, p)	0–0.73	0.25	0.21	.85
Sibling Problems (13a-n, p)	0–1	0.13	0.26	.95
Family Problems (13a-j)	0–0.88	0.13	0.21	.79
Stress Reaction (14a-c)	0–1	0.08	0.25	.83
Family Beliefs (15a, c, f, h)	0–1	0.27	0.30	.67
PedsQL				
Total	8–98	64.86	16.47	.92
Physical	9–100	63.57	18.37	.83
Psychosocial	7–97	65.45	17.53	.89

Note. Internal consistency calculated on data provided by patient, $n = 45$ for PAT, $n = 44$ for PedsQL.

the data well (i.e., $\chi^2_{1409} = 1,422.91$, $p = .39$, Root Mean Square Error of Approximation (RMSEA) = 0.015, CFI = 0.99, Weighted Root Mean Square Residual (WRMR) = 0.809).

Convergent Validity

Pearson correlations were conducted to assess convergent validity, that is, to determine whether PAT2.0_GEN AYA total and subscale scores were significantly negatively correlated with patient-reported quality of life. PAT2.0_GEN AYA total score was significantly negatively associated with patient-reported quality of life (see Table 3). There was a significant negative correlation between the PAT2.0_GEN AYA and the PedsQL Psychosocial ($r = -.34$, $p < .05$) and total scores ($r = -.35$, $p < .05$). Additionally, the PAT2.0_GEN AYA Child Problems subscale was significantly negatively correlated with the Psychosocial ($r = -.50$, $p < .01$), Physical ($r = -.34$, $p < .05$), and PedsQL total ($r = -.48$, $p < .01$) scores. The Family Problems subscale was also significantly negatively correlated with the Psychosocial ($r = -.48$, $p < .01$), Physical ($r = -.44$, $p < .01$), and PedsQL total ($r = .51$, $p < .01$) scores.

Predictive Validity

Logistic regression results that used observed PAT2.0_GEN AYA total scores as a predictor of whether (=1) or not (=0) an intervention referral was made showed that ($b_{logit} = 0.78$, $p = 0.06$, $\exp^{0.78} = 2.18$) the odds of participants receiving an intervention referral more than double (i.e., increased 218%) with each unit increase in PAT2.0_GEN AYA total score. This result raised an immediate question: Do all PAT2.0_GEN AYA subscale scores contribute

Table III. Pearson Correlations Between PAT2.0_GEN Subscales and Patient Report of Patient's Quality of Life

PedsQL	PAT2.0_GEN							
	Resources	Social support	Child problems	Sibling problems	Family problems	Stress reaction	Family beliefs	Total
Physical	.17	-.16	-.34*	-.02	-.44**	-.20	-.09	-.28
Psychosocial	-.03	-.09	-.50**	-.08	-.48**	-.33*	-.06	-.34*
Total	.05	-.12	-.48**	-.06	-.51**	-.31*	.01	-.35*

Note. See PedsQL scoring manual for description of physical and psychosocial (Psychosocial Health Summary Score) scoring.

equally to predicting the need for an intervention referral? A second logistic regression analysis was conducted using the seven latent factors (structure and resources, social support, child problems, sibling problems, family problems, stress reaction, and family beliefs) obtained from the construct validity CFA as predictors of intervention referral. Results showed that the latent factors of structure and resources ($b_{logit} = 4.10$, $p = .035$, $\exp^{4.10} = 60.54$) and stress reaction ($b_{logit} = 2.54$, $p = .016$, $\exp^{2.54} = 12.69$) significantly predicted the need for a referral. Specifically, participants were >60 times more likely to need a referral per unit increase in structure and resources, and >12 times more likely to need a referral per unit increase in stress reaction.

Discussion

AYAs with SCD experience psychosocial factors that increase their risk of disease management difficulties and poor health outcomes. The NHLBI has recommended routine assessment of these factors to improve access to care and decrease acute care utilization rates (Yawn et al., 2014). The PAT2.0_GEN AYA is a brief, psychosocial screener that AYAs with SCD could complete at clinic visits (Pai et al., 2008). This measure could identify families in need of psychosocial intervention. A recent study supports the clinical utility of the PAT2.0_GEN in pediatric SCD but most families participating had children 7–8 years of age (Karlson et al., 2012). The current study evaluates the AYA version of the PAT2.0_GEN in a sample of AYAs with SCD.

Internal consistency for the PAT2.0_GEN AYA was in the acceptable to excellent range (0.79–0.95) except for the items comprising the Family Beliefs (0.67) and Structure and Resources subscales (0.37). In general, these results are consistent with those from previous studies assessing the internal consistency of the PAT2.0_GEN with pediatric kidney transplant (total score = 0.82; subscales = 0.31–0.81; Pai et al., 2012), cancer (total score = 0.81; subscales = 0.62–0.81; Pai et al., 2008), inflammatory bowel disease (total score = 0.83; subscales = 0.44–0.76; Pai et al., 2014) and younger patients with SCD (total score = 0.84; subscales = 0.43–0.83; Karlson et al., 2012). The data also indicated that the seven-factor

CFA fit the data well. As a whole, these results support the utility of the PAT2.0_GEN AYA as a screening tool for psychosocial risk in AYAs with SCD. Embedding the assessment of psychosocial factors into routine clinical practice enhances providers' abilities to integrate patient and family expectations and goals into the treatment plan, a crucial step in increasing patient engagement, improving treatment adherence and reducing disparities in the quality of care (Yamada & Brekke, 2008).

Similar to the Karlson et al. study, the internal consistency for the Structure and Resources subscale items was in the unacceptable range. Several factors likely contributed to this finding. First, a review of responses to the items on this subscale indicated that some older AYAs completed the questionnaire in reference to them when asked about their parent's level of education and marital status. Future studies should reword items to ensure that respondents know if the item is asking about them or their caregiver. To test this, one could compare patient and caregiver responses on the PAT2.0_GEN AYA. Second, some AYAs may have not been fully aware of family transportation or financial needs and as a result, may have underestimated or overestimated any difficulties. Third, this finding may reflect heterogeneity in our sample with respect to family resources. Fourth, this subscale may benefit from including items that better reflect the experience of families of AYAs with SCD and/or better discriminate when there are difficulties (e.g., items assessing pain coping). Items could be generated from qualitative studies that examine psychosocial risk and resiliency in this population.

Consistent with results from previous studies (Karlson et al., 2012; McCarthy et al., 2009; Pai et al., 2008, 2014), the internal consistency for the Family Beliefs subscale items (1. The doctors will know what to do; 2. Family will be closer; 3. We can make good treatment decisions; 4. We're going to beat this) was poor. Test developers should consider dropping this subscale in subsequent versions of the measure.

Study findings provide preliminary data to support that the PAT2.0_GEN AYA is assessing psychosocial functioning as intended. Similar to findings for pediatric kidney transplant and inflammatory bowel disease samples (Pai et al., 2012, 2014), we found significant negative correlations between the PAT2.0_GEN AYA

total score and patient reported quality of life (PedsQL total score) in this population. Elicitation of psychosocial issues by the health care team can strengthen the alliance with families (Yamada & Brekke, 2008). This may be particularly important for patients with SCD as a recent study found that perceived trust with the medical team mediated the relationship between discrimination and adherence to treatment (Haywood et al., 2014).

PAT2.0_GEN AYA scores were associated with an increased likelihood of referral for intervention within 4 months supporting the predictive validity of the measure. More specifically, this was primarily driven by the Structure and Resources and Stress Reactions subscales. Intuitively, these findings make sense; the Structure and Resources subscale assesses psychosocial stressors such as transportation challenges, number of people in the home, and financial difficulties, whereas the Stress Reaction subscale gauges anxiety and worry. Owing to the lower internal consistency of the factor and the small sample size, these findings should be more closely examined and replicated with a larger sample.

The time period for referrals in this study (4 vs. 6 months for inflammatory bowel disease pediatric patients and 2 years for pediatric kidney transplant patients; Pai et al., 2012, 2014), but this timeframe was selected based on the schedule for clinic visits for AYAs in our sample. It also corresponds to the time-interval for repeat administrations in the Karlson et al. study. Because families with lower incomes often experience changes in psychosocial status that could adversely affect their child's health (e.g., losing housing; Cutts et al., 2011), repeat administration of the PAT2.0_GEN AYA may be warranted. If the PAT2.0_GEN AYA is administered only one time per year, psychosocial factors that significantly affect disease management (e.g., transportation problems) could be missed. Longitudinal studies using the PAT2.0_GEN AYA to assess psychosocial risk over time will answer questions about the optimal frequency for administration and the stability of the measure. A receiver operating characteristic (ROC) analysis would provide valuable information about the accuracy (positive or negative predictive value), sensitivity (accuracy among those who later sought treatment), and specificity (accuracy of those who have not sought treatment) of the PAT2.0_GEN AYA.

Study findings should be considered in the context of its limitations. First, this single site study included a small sample size, which limits the generalizability of results. We recommend additional validation studies to confirm this study's results and to examine the psychometrics of this measure with larger samples, across sites, for AYAs with other chronic diseases, and for racially, ethnically, and culturally diverse AYAs. Second, referral data were collected from the EMR. It is possible that we missed some referrals for patients seeking care

outside of the medical center. Future studies should consider asking participants whether they are receiving psychological or social work intervention, in addition to reviewing the EMR. Third, we were not able to evaluate other types of validity (e.g., discriminant validity). If studies show that the PAT2.0_GEN AYA has good discriminant validity, this would add to its clinical utility. Use of other measures to evaluate convergent validity (e.g., PedsQL SCD Module) is also recommended. Fourth, because this was an initial validation study, we did not report information on PAT2.0_GEN AYA cut-off scores for each of the risk categories (universal, targeted, clinical); examining mean scores across studies will be an important step in building the literature base on the PAT2.0_GEN AYA in pediatric SCD. It will also be important to determine if the PAT2.0_GEN AYA identified any families who should have been referred for intervention but were not.

To conclude, study findings support the overall utility of the PAT2.0_GEN AYA as a brief psychosocial screener for AYAs with SCD that could be feasibly administered in the context of clinical care. Use of this measure would increase the health care team's capacity for systematic assessment of psychosocial needs in everyday practice. Clinicians could use items from the PAT2.0_GEN AYA as a starting point to elicit more in-depth information about psychosocial needs and how they might affect the family's ability to adhere to treatment. If the PAT2.0_GEN AYA could identify vulnerable families, then it could function in a clinical decision-making capacity. Based on PAT 2.0_GEN results, referrals could be made, psychosocial factors addressed, and the impact of these factors on disease management minimized, ultimately resulting in improved health outcomes.

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