

The Kennedy Krieger Independence Scales–Spina Bifida Version: A Measure of Executive Components of Self-Management

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Purpose/Objective: Successful implementation of functional self-care skills depends upon adequate executive functioning; however, many scales assessing adaptive skills do not address the inherent executive burden of these tasks. This omission is especially relevant for individuals with spina bifida, for whom medical self-care tasks impose a significant burden requiring initiation and prospective memory. The Kennedy Krieger Independence Scales–Spina Bifida Version (KKIS–SB) is a caregiver-reported measure designed to address this gap; it assesses skills for managing both typical and spina bifida-related daily self-care demands, with a focus on the timely and independent initiation of adaptive skills. **Research Method/Design:** Parents of 100 youth and young adults with spina bifida completed the KKIS–SB. Exploratory factor analysis and Pearson’s correlations were used to assess the factor structure, reliability, and construct validity of the KKIS–SB. **Results:** The scale demonstrates excellent internal consistency (Cronbach’s alpha = .891). Exploratory factor analysis yielded four factors, explaining 65.1% of the total variance. Two primary subscales were created, initiation of routines and prospective memory, which provide meaningful clinical information regarding management of a variety of typical (e.g., get up on time, complete daily hygiene routines on time) and spina bifida-specific self-care tasks (e.g., begin self-catheterization on time, perform self-examination for pressure sores). **Conclusions/Implications:** Based upon internal consistency estimates and correlations with measures of similar constructs, initial data suggest good preliminary reliability and validity of the KKIS–SB.

Keywords: transition, adaptive functioning, validity, factor structure, executive function

Impact and Implications

- The life expectancy of individuals with spina bifida has increased considerably during the past several decades due to medical advances and public health policies, but little research has been conducted concerning the transition of these individuals from adolescence into adulthood.

- The current study helps address this research gap by presenting cross-sectional normative data spanning a broad transition period (i.e., age 10 to 29) using a new instrument (KKIS–SB) designed to assess medical self-management competencies and executive behaviors in individuals with spina bifida.

- Findings from this study suggest a broad range of functioning in self-care, self-management, and executive behaviors among individuals with spina bifida, as well as a general pattern of improvement and development over time. Use of the KKIS–SB is recommended as a component of assessment to help monitor self-care and self-management skill development over time and assess readiness for less restrictive/supportive settings encountered in young adulthood.

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Introduction

Spina bifida is a neural tube defect that has become increasingly survivable, due in great part to medical advances including shunting of hydrocephalus (Aschoff, Kremer, Hashemi, & Kunze, 1999; Boockvar, Loudon, & Sutton, 2001), clean intermittent bladder catheterization (Lapides, Diokno, Gould, & Lowe, 1976), vaccination against *Haemophilus influenzae* (Hib) Type B (Centers for Disease Control & Prevention, 2008), and use of brain imaging technology such as computed tomography and magnetic resonance

imaging (Vogl, Ring-Mrozik, Baierl, Vogl, & Zimmermann, 1987) to identify acute periods of hydrocephalus. Despite increased survival rates, individuals with spina bifida often struggle to attain independence in their adult functioning. Adults with spina bifida have high levels of unemployment (Blomquist, 2006; Johnson, Dudgeon, Kuehn, & Walker, 2007), and the majority live with their parents or in other supportive settings (Boudos & Mukherjee, 2008; Johnson et al., 2007). Moreover, adults with spina bifida are frequently hospitalized (Dicianno & Wilson, 2010) due to preventable conditions such as urinary tract infections and pressure ulcers (Kinsman & Doehring, 1996). In response to these poor distal outcomes, there has been increased emphasis on the acquisition of self-management competencies during adolescence to help reduce the occurrence of preventable health-related conditions and the need for restrictive care during adulthood (e.g., Buran, Brei, Sawin, Stevens, & Neufeld, 2006; Mukherjee, 2007).

Developmental research suggests that skills central to self-management and autonomy in spina bifida (e.g., independent toileting/catheterization) appear to develop in a delayed manner (Davis, Shurtleff, Walker, Seidel, & Duguay, 2006; Schoenmakers, Gulmans, Gooskens, & Helders, 2004), with adolescents and young adults with spina bifida often maintaining a pattern of dependence upon their caregivers with respect to specialized self-management tasks (Blum, Resnick, Nelson, & St. Germaine, 1991). The underpinnings of the delay and ongoing dependence in self-management skills are likely multifactorial, including contributions from physical characteristics, level of knowledge/skill, intelligence, and available family support. There is also growing evidence that deficits in executive functioning (e.g., planning, initiating, problem-solving) mediate the impact of neurological severity upon functional independence (Heffelfinger et al., 2008). As there is considerable evidence of executive dysfunction in this patient population in general (Brown et al., 2008; Fletcher, Brookshire, Bohan, Brandt, & Davidson, 1995; Mahone, Zabel, Levey, Verda, & Kinsman, 2002; Rose & Holmbeck, 2007; Tarazi, Zabel, & Mahone, 2008; Zabel, Jacobson, Zachik, Levey, Kinsman, & Mahone, 2011), we have proposed that the combination of increased adaptive skill requirements combined with the features of executive dysfunction observed in spina bifida create a unique self-care burden requiring both skill instruction and accommodation for executive deficits (Tarazi, Mahone, & Zabel, 2007).

At present, there are few specialized assessment tools available to evaluate self-care skills and self-management competency in spina bifida. Commercially available adaptive skill inventories (e.g., Adaptive Behavior Assessment System – Second Edition [ABAS-II]; Harrison & Oakland, 2003; Vineland Adaptive Behavior Scales; Sparrow, Balla, & Cicchetti, 1984) have been used to track ongoing development in spina bifida (Davis et al., 2006), but these inventories do not typically include item content specific to spina bifida-related self-care expectations (e.g., clean intermittent catheterization, specialized bowel continence programs, skin inspection for pressure sores, etc.), as these types of self-management tasks are infrequently required of children and adolescents in general. Although development of self-care competencies appears critical to acquisition of independence, there are few measures of adaptive functioning containing item content specific to spina

bifida. One such instrument is the Adolescent Self-Management and Independence Scale-2 (AMIS-2; Buran et al., 2006), a structured clinical interview developed to assess knowledge and behavior regarding spina bifida management as well as general activities of daily living. Research involving the AMIS-2 has been promising with regard to psychometric properties as well as its potential for assessing spina bifida specific competencies and associations with concurrent adult outcomes (Bellin et al., 2011; Buran et al., 2006). It is important to note, however, that the AMIS-2 relies solely upon self-report for the assessment of individuals' self-management capabilities. While self-report is an important source of information regarding adolescent and young adult functioning, complementary informant reports (e.g., parents) of self-management are also needed. Significant inconsistency has been reported between self-assessment and parent-assessment of the behavioral and executive functioning of adolescents with spina bifida (Mahone et al., 2002; Zabel et al., 2011), and significant cognitive deficits have been reported in youth with spina bifida (Dennis & Barnes, 2010) that could detract from the accuracy of self-assessment. As such, parent/informant reports are an important component of assessing development of critical self-care competencies.

The Kennedy Krieger Independence Scales – Spina Bifida Version (KKIS-SB; Zabel, Jacobson, Tarazi, & Mahone, 2012) is a parent report inventory measuring the frequency with which individuals with spina bifida initiate and complete both typical and condition-related daily self-care demands. The scale was designed to supplement traditional assessment of adaptive functioning and examine condition-related competencies in adolescents and young adults with spina bifida. The content and structure of the KKIS-SB is organized to present questions concerning the level of basic adaptive skill shown by the adolescent or young adult with spina bifida as well as the independent initiation and completion of such skills. Initial item content of the KKIS-SB was generated by way of review of relevant literature, focus groups composed of multidisciplinary medical and rehabilitation professionals with experience providing spina bifida related care (i.e., psychologists, neurologists, physiatrists, occupational therapists, physical therapists), and interviews with individuals with spina bifida and their parents/caregivers. Focus groups and interviews were organized to generate item content, with an emphasis upon identifying skill areas thought to pose the greatest challenge to individuals with spina bifida as they assumed increased responsibility for their own self-care and medical self-management. Participants in focus groups and interviews were encouraged to identify self-management challenges specific to spina bifida (e.g., self-catheterization) as well as transitional issues with less condition-related specificity (e.g., chores, food preparation, social initiation). These focus groups included participants with spina bifida who had attained common indicators of successful transition into adulthood (e.g., college, independent living, part- or full-time employment) and could reflect upon their transition process. Several iterations of item generation, refinement, and reduction were conducted, with parent and patient feedback elicited regarding the cultural sensitivity and readability of item content. Final item content and test format was further evaluated via parent feedback obtained during usability trials performed in the context of clinic visits.

Study Objectives

Clinical utility and validity of the KKIS–SB were established through two related studies. In Study 1, we recruited a representative sample of participants (i.e., parents of individuals with spina bifida) who completed the KKIS–SB assessing the daily adaptive functioning of their children with spina bifida. These responses established initial normative data for individuals with spina bifida, as clustered by age groups. We then examined psychometric properties of the KKIS–SB, including internal consistency, factor structure, and associations of total KKIS–SB scores and subscales with age. We hypothesized that the KKIS–SB would provide a reliable measure of spina bifida specific self-care skills as well as typical daily demands expected of youth and young adults, and that ratings of these skills would show the expected association with age. In Study 2, we recruited a smaller sample of participants (i.e., parents of individuals with spina bifida) who completed the KKIS–SB, as well as additional commercially available measures of adaptive (ABAS-II) and executive function behaviors (Behavior Rating Inventory of Executive Function [BRIEF, Gioia, Isquith, Guy, & Kenworthy, 2000]). We then examined associations of the ratings on the KKIS–SB with ratings of adaptive and executive behaviors as evidence for concurrent validity of the KKIS–SB subscales. We hypothesized that the KKIS–SB total and subscale scores would show a positive association (i.e., convergent validity) with scores on scales measuring relevant aspects of self-care/activities of daily living (i.e., ABAS-II self-care [“brushes teeth”] and home living [“cleans room regularly”] scales) and metacognitive aspects of executive functioning (i.e., BRIEF Initiate [“needs to be told to begin a task even when willing”] and working memory [“has trouble remembering things, even for a few minutes”] scales). In addition, the KKIS–SB total and subscale scores were hypothesized to show little association (i.e., discriminant validity) with scores on scales thought to be less related to the constructs measured by the KKIS–SB (e.g., ABAS-II social [“stands a comfortable distance from others during conversations”], BRIEF emotional control [“overreacts to small problems”] scales).

Methods

Participants

Study 1. Study 1 examined the internal consistency and factor structure of the KKIS–SB. The study was approved by the Johns Hopkins University School of Medicine Institutional Review Board (IRB). Participants were recruited to anonymously complete a web-based survey that included the KKIS–SB and relevant demographic information, not including personal health or identifying information. Recruitment was conducted through local and national spina bifida organizations, spina bifida-specific online listservs and chat groups, paper and e-mail organization newsletters sent to members, patient contact in the KKI Philip A. Keelty Center for Spina Bifida and Related Conditions (KKI SBC), and flyers sent to spina bifida clinic providers in locations across the country. Parents were asked to complete the survey via a secure, electronic web-based platform (psychdata.com).

Parent ratings were acquired for individuals with spina bifida between the ages of 10 and 29. Survey logic routed parents of

individuals between the ages of 10 and 17 directly to the item content. If the individual being rated was a young adult, the survey logic directed parents to enter their child’s e-mail address (not retained) in order to initiate a request for permission to complete the survey. An automatically generated e-mail request was then sent, and the young adult was invited to log in to a self-report version of the questionnaire via a link provided in the e-mail. If the young adult with spina bifida consented to his or her parent’s completion of the survey, he or she was asked to generate a password that the parent could use to access the parent-report version of the survey. Once the password was entered, the webhost program automatically e-mailed the password back to the parent. Parent ratings of individuals between the ages of 18 to 29 were only maintained in the database if the parent responses were accompanied by a password matching a corresponding password from the young adult self-report version of the KKIS–SB.

In total, 227 individuals attempted to participate and began the online parent-report measure. The following were excluded from the sample: 99 parents/caregivers indicated that the individual to be rated was not within the study age range (i.e., was younger than 10 years or older than 29), 17 parents/caregivers provided incomplete responses on the measure, six young adults with spina bifida provided self-reports on the parent version, four youth had two caregivers complete the ratings (in these cases, only maternal responses were retained in the sample) and one rating was completed by a foster parent (which was an exclusion criteria); as such, 127 ratings were subsequently excluded from the sample, resulting in 100 remaining complete ratings.

Using this recruitment method, parents of 100 youth and young adults completed the survey, including a demographic questionnaire and the KKIS–SB. Of the complete caregiver ratings, 29 ratings came from parents of individuals between the ages of 18 and 29, and included a password that matched a password generated in the young adult self-report version of the KKIS–SB. Reporters were primarily mothers (94%), and most were college graduates (40%) with a substantial proportion completing a graduate or professional degree (22%). Of those with less education, 16% had a high school education and 22% completed trade school or some college coursework.

Although respondents were asked several questions designed to ensure that individuals being rated had a medical diagnosis of spina bifida, no independent verification could be obtained from the individual’s physician due to the anonymous nature of the data collection model. Of the youth and young adults with spina bifida, the majority were reported to have lumbar level lesions (69.4%; 12.2% thoracic, 18.4% sacral, 2% unknown) and hydrocephalus (87.0%; 95.4% of those were shunted and 89.2% had ≥ 1 shunt revision). Most ambulated with assistance (23% walked independently; 29% used an assistive device or AFO, 69% used a wheelchair at least outside of the home). Youth were included in the sample if they were between ages 10 and 29 (mean [*M*] age = 16.77, standard deviation [*SD*] = 5.68). Of the young adults (e.g., over age 17), 48.3% were still living with parents, and the remainder were living either alone or with a friend or spouse in the community. The majority of the individuals rated were male (54%) and Caucasian (94%); 4% were African American, 1% Asian, and 1% were American Indian/Alaskan Native; of this sample, 7% were of Hispanic ethnicity. Although a large proportion of participants (29%) came from the Kennedy Krieger Institute’s immedi-

ate catchment area (i.e., Maryland, Virginia, Washington DC, Delaware, and New Jersey), regions across the United States were represented in the sample: 46% from the South, 26% from the Northeast, 23% from the Midwest, and 9% from the West.

Study 2. Study 2 examined the convergent and discriminant validity of the KKIS-SB (Total score and subscale scores) in comparison with commercially available measures of adaptive (ABAS-II) and executive functioning (BRIEF). Of note, the KKIS-SB was presented to participants in a paper form to facilitate ease of completion (i.e., the paper version of the KKIS-SB was presented to participants in a packet with paper versions of the ABAS-II and the BRIEF). The study was approved by the Johns Hopkins University School of Medicine IRB. Parents of 22 youth and young adults with spina bifida ($M_{\text{age}} = 14.18$, $SD = 3.66$, range = 8–20 years), treated at the KKI SBC, were recruited in conjunction with clinic visits and consented in accordance with IRB procedures. Youth with spina bifida gave written assent to participate. Of this sample, 18 were below the upper age-limit for the BRIEF normative sample (e.g., age 18), which allowed for comparison between the BRIEF and KKIS-SB. The majority were female (59.1%) and had lumbar level lesions (59.1%; 22.7% thoracic, 9.1% sacral), shunted hydrocephalus (95.5%; 86.4% with ≥ 1 shunt revision), and ambulated independently (50.0%; 40.9% used a manual wheelchair and 9.1% used a motorized wheelchair). Most of the sample was required to complete daily self-catheterization (86.4%).

Measures

KKIS-SB (Zabel et al., 2012). As described above, the KKIS-SB is a parent- and self-report measure of medical and self-care aspects of adaptive functioning and self-management competencies specific to spina bifida. It was designed to assess skills for managing both typical and disease-related daily self-care demands, with a focus on the timely initiation of adaptive skills. Items relating to typical adaptive demands include those addressing managing morning routines, completing daily chores, and interacting appropriately with others. Items assessing atypical medical self-care demands include spina bifida-specific items relating to bowel and bladder programs, as well as other medical self-care competencies such as medication adherence and managing medical care appointments. The measure consists of 18 skill-based items, four items assessing parental expectations related to development of key self-care competencies, and an overall safety judgment rating. For the skill-based items, parents were asked to indicate their level of confidence that the child being rated would perform the specific skill, independently, without help or reminders. Response options included “Yes” (i.e., the task in question would be completed at least 90% of the time), “Maybe” (10–90% of the time), or “No” (less than 10% of the time), and were coded as 3, 2, or 1, respectively, with higher scores indicative of greater independence with self-care. Importantly, although the majority of individuals with spina bifida are typically required to manage the demands of neurogenic bladder and bowel as well as skin self-examination, this is not true for all cases; “not applicable” responses were available for selected items. Because the KKIS-SB is a competency-based measure, full credit (3) was awarded for not applicable ratings on items pertaining to specific medical or spina bifida-related self-care tasks (e.g., full credit was awarded on the “takes medication on time” item if the individual being rated was not required to take medication). In

contrast, minimal credit (1) was awarded for not applicable responses on items with less condition-related specificity, as these were thought to have transitional implications (e.g., minimal credit was awarded on the “completes chores on time” if the individual being rated did not have an assigned chore). The total KKIS-SB score, consisting of responses on the skill-specific items, ranged from 18–54. Initial psychometric data are presented below (Study 1). The KKIS-SB was recently made available for clinical and research use on several electronic systems, that is, the Child Health and Development Interactive System (CHADIS; www.chadis.com) and PsychData (www.psychdata.com); additional platforms are under consideration.

ABAS-II (Harrison & Oakland, 2003). The ABAS-II is a parent-report questionnaire assessing functional skills for managing age-appropriate daily expectations across home and community settings. The ABAS-II comprises items assessing adaptive functioning within nine primary skill areas, communication, functional academics, self-direction, leisure, social, community use, home living, health and safety, and self-care. All of the individual skill areas contribute to a general adaptive composite (GAC). A tenth skill area, work skills, can be administered to older adolescents and young adults, but was not included as part of this study. The ABAS-II GAC has strong internal consistency (Cronbach’s $\alpha = .98$) as do the skill area scores (Cronbach’s $\alpha = .95 - .97$). Stability over time also is strong (GAC corrected test-retest reliability $r = .93$, skill area corrected test-retest $r = .84 - .92$).

BRIEF (Gioia et al., 2000). The BRIEF is a parent-report questionnaire assessing executive function behaviors in children 5–18 years old. Executive behaviors involve the regulation of cognitive, emotional, and behavioral functioning in order to engage in effective problem-solving behavior. The BRIEF items are organized into eight individual scales, subsumed under two factors and one overall composite score. Individual subscales reflect the child’s ability to shift cognitive set (shift scale), employ inhibitory control (inhibit scale), modulate emotions and behavior (emotional control scale), initiate tasks (initiate), sustain information in working memory (working memory), plan and sustain a problem-solving approach (plan/organize), organize materials and belongings (organization of materials), and self-monitor performance and/or progress toward a goal (monitor). The global executive composite (GEC) is a composite of all subscales. Internal consistency for the GEC is high ($r_{\alpha} = .98$), with good test-retest reliability ($r = .81$). The BRIEF has been shown to be sensitive in identifying patterns of behavior associated with executive dysfunction in adolescents and young adults with spina bifida (Mahone et al., 2002; Tarazi et al., 2008; Zabel et al., 2011).

Data Analysis

Study 1. Exploratory factor analysis was conducted on the 18 primary items of the KKIS-SB to determine the component structure of this measure. Factors were extracted using principal axis factoring, with Promax rotation. Next, internal consistency (Cronbach’s α) was examined for the total score and the subscales (primary factors). One-way between-subjects analysis of variance (ANOVA) was used to test for differences in KKIS-SB total and subscale scores across age groups.

Study 2. Performance of the second sample on the KKIS-SB was compared to published normative means of existing parent report measures of adaptive skills (ABAS-II) and executive func-

tion behaviors (BRIEF). Associations (e.g., correlations) between the KKIS–SB total and subscale scores and measures of adaptive skills and executive behaviors were examined to provide preliminary data regarding construct validity of the KKIS–SB. Given the number of potential correlations to be examined, the KIS initiation of routines and prospective memory factors were hypothesized a priori to correlate most strongly with measures of self-care, home living, self-direction, and initiation, but not with ratings of social skills or emotional control.

Results

Study 1

Exploratory factor analysis (EFA) of the KKIS–SB items was conducted in two stages, using principal axis factoring with Promax rotation. Initial EFA of the KKIS–SB skill-based items extracted five factors accounting for 70.6% of the total variance. However, the later factors consisted of few items, with several cross-loading items; given high correlations between two of the items relating to bowel program implementation (i.e., “start bowel program on time” and “complete bowel program independently,” $r = .747$), the second of these items was dropped from further analyses. From the 17 remaining items, EFA extracted four factors, explaining 65.1% of the variance, with few significant cross-loadings (see Table 1). Factors were determined to be significant based upon eigenvalues above 1.0 and examination of the scree plot.

The first two factors were composed of six items each, whereas remaining factors were less robust and contained fewer items, suggesting less utility as stable and unique factors. As a result, the first two factors were retained as clinically useful subscales of the KKIS–SB. All items were retained as contributing to the KKIS–SB total score. The first factor, accounting for 37.2% of the variance,

was defined by items representing initiation of daily self-care and home living routines (e.g., “start self-catherization on time,” “finish morning hygiene routine on time”); the subscale was subsequently named initiation of routines. The second factor, accounting for 11.5% of the variance, was indexed by items reflecting the ability to “remember to remember” to complete a task, or prospective memory (e.g., “look for pressure sores,” “arrange for transportation”). The final two factors, accounting for 9.36% and 7.12% of variance, respectively, included items related to social engagement (e.g., “attempt to contact a friend”) and medical communication skills (e.g., “provide accurate medical information”).

Preliminary data suggest that the KKIS–SB total score and the subscales derived from the first two factors provide reliable measures of specific aspects of adaptive skill implementation for this population. Initial internal consistency of the total KKIS–SB scale, consisting of the 18 skill-based items was excellent (Cronbach’s $\alpha = .891$). Two subscales were created based upon unit-weighting of items loading onto the first two factors. Internal consistency estimates for the initiation of routines and prospective memory subscales were also strong (Cronbach’s $\alpha = .870$ and $.815$, respectively).

In this cross-sectional cohort study, the KKIS–SB total score and the subscales showed significant associations with age (KKIS–SB total: $r = .628$, $p < .001$; initiation of routines subscale: $r = .511$, $p < .001$; prospective memory subscale: $r = .589$, $p < .001$). To permit more specific analysis of age-related differences, the sample was divided into four groups (see Figure 1): children (ages 10–12, $n = 26$), adolescents (ages 13–16, $n = 35$), college-age youth (ages 17–22, $n = 17$), and young adults (ages 23–29, $n = 22$). One-way between subjects ANOVA revealed a significant relationship between increased age and greater independence in young adulthood for the total KKIS–SB score [$F_{(3,96)} = 20.176$, $p < .001$, $\eta^2 = .387$], the initiation of routines subscale [$F_{(3,96)} = 9.432$, $p < .001$, $\eta^2 = .228$], and the prospective memory subscale [$F_{(3,96)} = 17.949$, $p < .001$, $\eta^2 = .359$]. Using Bonferroni correction for multiple comparisons, post hoc analyses for the initiation of routines subscale revealed significant differences in parent report of child initiation between each of the younger age groups and the young adult group (all $p \leq .05$). For the prospective memory subscale, post hoc analyses revealed similar findings: the young adult group was reported to show better prospective memory for self-care tasks than each of the younger groups (all $p < .01$). College-age youth were also reported to show significantly stronger prospective memory than the youngest age group ($p = .049$).

Additionally, for individuals over the age of 18 ($n = 29$), young adults living in the community were reported by parents as likely to have better adaptive self-competence overall, as compared with those still living at home with parents [KKIS–SB total score: $t_{(27)} = -3.356$, $p = .002$]. After controlling for effects of age, parents who rated their children (of any age) as showing better adaptive self-care overall (e.g., higher total KKIS–SB scores) were more likely to report that their child would be safe if left alone for an entire day ($r_p = .391$, $p < .001$).

Study 2

Validation of the KKIS–SB was explored in a separate sample of youth with spina bifida. Parents of 22 youth with spina bifida

Table 1
Kennedy Krieger Independence Scales—Spina Bifida Version
Item Factor Loadings

Item	Factor ^a			
	1	2	3	4
Keep room clean	.893			
Finish chores	.845			
Catheterize on time	.597			.317
Out of bed on time	.547			
Hygiene on time	.475			.335
Take medication on time	.442			
Arrive at appointment on time		.898		
Arrange transportation		.813		
Look for pressure sores		.630		
Start bowel program		.600		
Perform pressure relief		.555		
Write scheduled appointments		.454	.294	
Contact friend			.828	
Spend time with friend			.763	
Provide accurate medical information			.292	.696
Complete catheterization				.636
Ask doctor appropriate questions			.401	.540

Note. $N = 100$. Factor loadings $< .25$ are not reported.

^a Factor 1: initiation of routines. Factor 2: prospective memory.

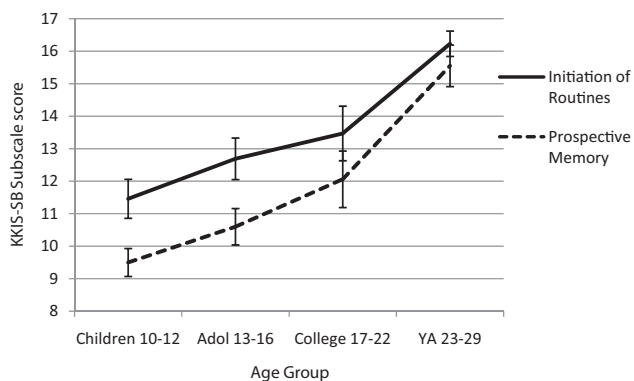


Figure 1. Age-related change for KKIS-SB subscale scores. Note. Bars represent standard error. Scores ranged from 6–18 for both scales. KKIS-SB = Kennedy Krieger Independence Scales–Spina Bifida Version; Adol = Adolescent; YA = Young Adult.

treated at the KKI SBC completed the KKIS-SB along with additional measures of adaptive skill (ABAS-II; $N = 22$) and executive function behaviors (BRIEF; $n = 18$). Relative to published normative data, participants in this sample were rated by their parents as showing impairments in both adaptive skills, ABAS-II GAC: $M = 85.95$, $SD = 22.14$, $t_{(20)} = -.291$, $p = .009$, and executive function behaviors, BRIEF GEC: $M = 61.59$, $SD = 12.23$, $t_{(16)} = 3.91$, $p = .001$. Based upon the factor structure of the KKIS-SB observed in Study 1, KKIS-SB subscale scores were computed for the two primary factors: initiation of routines and prospective memory.

Evidence for convergent validity of the KKIS-SB was provided by significant correlations of the KKIS-SB initiation of routines and prospective memory subscales with the home living, self-care, and self-direction subscales of the ABAS-II (all $p < .01$; see Table 2). As hypothesized, the KKIS-SB initiation of routines subscale was also significantly correlated with the BRIEF initiate subscale ($r = -.558$, $p = .02$; see Table 3). In fact, the KKIS-SB initiation of routines scale correlated with most BRIEF scales, suggesting shared measurement of executive functioning behaviors (inhibition, shifting, initiation, working memory, and self-monitoring) required for daily adaptive competence. In contrast, the prospec-

Table 3
Correlations Between KKIS-SB Subscales and BRIEF Scales

	Initiation of routines	Prospective memory
BRI	-.531*	-.228
MI	-.569*	-.333
Inhibit	-.664**	-.324
Shift	-.505*	-.052
Emotional control	-.293	.012
Initiate	-.558*	-.388
Working memory	-.624**	-.190
Plan/organize	-.438	-.064
Organization of materials	-.304	.013
Monitor	-.535*	-.174

Note. $N = 18$. KKIS-SB = Kennedy Krieger Independence Scales, Spina Bifida Version; BRIEF = Behavior Rating Inventory of Executive Functioning; BRI = BRIEF Behavior Regulation Index; MI = BRIEF Meta-cognition Index.
* $p < .05$. ** $p < .01$.

tive memory subscale did not correlate with any of the BRIEF scales (all $p > .05$). With regard to discriminant validity, associations were nonsignificant between the KKIS-SB subscales and measures of social skills (ABAS-II social scale) and emotional functioning (BRIEF emotional control scale).

Discussion

These findings provide initial psychometric support for the KKIS-SB as a parent-report measure of executive components of specialized self-management in adolescents and young adults with spina bifida. The initial normative sample of the KKIS-SB represents all major geographic regions of the United States and is consistent with national data regarding relevant medical background variables in this population such as lesion level, shunt status, and mobility. The scale demonstrates excellent internal consistency and the item content represents an expansion of adaptive skill assessment possibilities beyond what is typically available for this specialized medical population. Within this cross-sectional cohort, KKIS-SB scores correlated strongly with age. This association is thought to track a trend toward greater independence shown by youth with spina bifida as they approach and enter young adulthood. Exploratory factor analysis yielded two reliable subscales of the KKIS-SB, initiation of routines and prospective memory, which provide meaningful clinical information regarding both typical (e.g., get up on time, complete daily hygiene routines on time) and spina bifida-specific daily self-care tasks (e.g., begin self-catheterization on time, perform self-examination for pressure sores). Finally, convergent validity was demonstrated via the pattern of correlations with specific scales of existing measures of adaptive skills and behaviors associated with executive function.

The KKIS-SB is not intended to replace more comprehensive measures of traditional aspects of adaptive functioning. However, when added to the limited pool of such psychological and neuropsychological instruments, the KKIS-SB provides a highly specialized assessment of the adaptive skills and self-management capabilities specific to youth and young adults with spina bifida. Notably, the prospective memory subscale of the KKIS-SB appears to measure a construct not captured by current parent-report

Table 2
Correlations Between KKIS-SB Subscales and ABAS-II Scales

	Initiation of routines	Prospective memory
Communication	.674**	.308
Community use	.561**	.595**
Functional academics	.495*	.434*
Home living	.649**	.560**
Health and safety	.597**	.453*
Leisure	.489*	.416
Self-care	.708**	.584**
Self-direction	.832**	.660**
Social	.342	.330

Note. $N = 22$. KKIS-SB = Kennedy Krieger Independence Scales, Spina Bifida Version; ABAS-II = Adaptive Behavior Assessment System – Second Edition.
* $p < .05$. ** $p < .01$.

measures of executive behaviors (i.e., the BRIEF). Items on the prospective memory subscale require the individual with spina bifida to begin a specific task (i.e., remember to remember to . . .) at a given time or within a given time period, with or without clear cues or reminders. Items assessing similar skills do not appear on the BRIEF, which may account for the limited correlation between this scale and the BRIEF subscales. These skills are thought to be predictive of adult independence, thus the KKIS–SB provides a valuable tool for assessment of capabilities required for successful transition. In addition to assessing condition-related self-management capabilities, the KKIS–SB facilitates the assessment of specific executive control behaviors thought to underlie the independent use and initiation of the self-management tasks common in spina bifida. Given the executive impairments commonly observed among individuals with spina bifida (Tarazi et al., 2008; Zabel et al., 2011), the KKIS–SB adds a unique and important component to assessment of adaptive competence. Furthermore, the wide age span utilized in the development of the KKIS–SB allows for a more comprehensive evaluation of the transition of individuals with spina bifida moving from adolescence into adulthood.

Limitations

One limitation of the present study is the likelihood of selection bias in this sample. Although use of an online platform for data collection enabled recruitment of participants from across the country, use of online data collection may have biased the sample toward those individuals most comfortable using technology and responding to online recruitment strategies. These individuals may not be representative of the entire population of youth and young adults with spina bifida and their caregivers. An additional limitation concerns the consent process involved for recruitment of parents of young adults. Given the complexity of the multiple-e-mail consent process for young adults and their parents/caregivers, it may be that those young adults participating in the study (e.g., who gave consent to their parents via the survey e-mail procedure) demonstrate a generally higher level of intellectual and/or executive skills overall than those who did not participate (e.g., failed to respond to their parent's request for permission to complete the survey, were not comfortable using e-mail, and/or were unable to navigate the electronic interface). As a result, it is possible that results are slightly skewed toward better adaptive and executive competence, at least for the young adult portion of the sample. A sample obtained using an in-clinic facilitated consent process may yield slightly different findings. Furthermore, use of clinic-based samples would permit concurrent assessment of cognitive ability; the current findings are limited by the lack of information regarding the cognitive functioning of the youth and young adults for whom ratings were provided by their parents.

These initial findings suggest that the KKIS–SB is a reliable measure of specific aspects of self-care competence for youth and young adults with spina bifida. Although initial estimates of internal consistency were strong, further examination of stability of the measure (i.e., reliability over time, or test–retest reliability) will be important for future clinical use of the KKIS–SB in tracking ongoing development of these skills during the transition into adulthood. Stability of the KKIS–SB will be examined based upon ongoing accrual of additional normative data and repeated assess-

ment of individuals over time using the available electronic host platforms and collaboration with providers and spina bifida-specific care clinics across the country.

Future Directions

Future investigations with the KKIS–SB will extend into several directions, each of which will expand the clinical utility of the instrument. First, given the prevalence of spina bifida among youth of Hispanic ethnicity, an English-only parent-report measure is likely to have limited clinical utility in specific regions of this country and abroad. Thus, future plans include translation of the measure into Spanish to increase the accessibility. Second, given the importance of executive components of self-care to successful transition into adulthood, and the increasing survivability of a number of other neurodevelopmental disorders, the KKIS–SB provides a framework for developing additional tools to assess both typical and condition-specific adaptive competencies in a variety of conditions. The proportion of youth with specialized health care needs transitioning into adulthood in this country continues to grow, and thus, the need for measures that can appropriately assess and target supportive interventions to these youth also continues to grow. We believe that the KKIS–SB provides a model for assessing critical, but until now overlooked, components of adaptive competence in youth with specialized health care needs. Development of additional modules of the KKIS to address disease-specific self-care competencies is in process for additional health conditions which also place an increased self-care demand upon youth and young adults while simultaneously affecting their cognitive development (e.g., hydrocephalus, sickle cell disease, etc.). These additional KKIS instruments are intended to add to the ability of health care providers to identify and intervene in areas critical to successful transition into young adulthood. The KKIS–SB and its future “siblings” fill the gap between assessment of relevant adaptive skills and more “executive” self-regulation behaviors that support use of these skills, allowing for more accurate and specific identification of those hurdles faced by youth with specialized health care needs as they seek to live independently, obtain gainful employment, and maintain their health successfully.

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