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## RESEARCH ARTICLE

WILEY

# Trajectories of self-management and independence in youth with spina bifida: Demographic predictors of growth

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## Abstract

**Aim:** The purpose of this study was to examine the trajectories of condition and independent living self-management in youth with spina bifida (SB).

**Methods:** A diverse sample of adolescents and young adults (AYAs) with SB completed the Adolescent/Young Adult Self-Management and Independence Scale (AMIS-II) across four time points. Parents reported on demographic characteristics including age, sex, race/ethnicity, and family income. Growth in self-management and its subscales (condition and independent living) were estimated using linear mixed-effect models as a function of respondents' demographics.

**Results:** This study included 99 respondents age 18 to 27 years old. About half were female (52.5%) and White (52.5%); 15.2% were Black, and about a third were Hispanic/Latino (32.3%). Eighty-seven AYAs (87.9%) had myelomeningocele. The lesion level was 31.3% sacral, 48.5% lumbar and 18.2% thoracic. A third of the families earned less than 50K. Overall, self-management growth was dependent on age, sex, and race/ethnicity, but not income. Growth in condition self-management depended on sex; only males demonstrated increasing growth ( $\hat{\beta} = 0.11$ ,  $p < 0.001$ ). Black participants endorsed higher increasing total and condition self-management when compared with White ( $\hat{\beta}_{diff} = 0.17$  and  $0.17$ , respectively, both  $p < 0.05$ ) and Hispanic/Latino ( $\hat{\beta}_{diff} = 0.18$  and  $0.21$ , respectively, both  $p = 0.02$ ) respondents.

**Conclusion:** This study provides evidence of differences in growth of self-management by demographic/social determinants of health. Possible reasons for differences are discussed. Predictors of changes in self-management behaviours over time in young adults with SB can identify subgroups in need of further study.

## KEYWORDS

adolescents, independence, self-management, spina bifida, trajectory, young adults

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## 1 | INTRODUCTION

Spina bifida (SB) is a complex congenital condition involving the central nervous system, which results in secondary conditions and complications [Copp et al., 2015; National Institute of Neurological Disorders and Stroke (NINDS), 2013]. Youth experience physical disabilities, orthopaedic conditions, shunt surgeries, and alterations in bowel and bladder patterns, which require complex care regimens. Parents share responsibility for care with youth and may do so in varying amounts over adolescence and young adulthood; the long-term goal for most youth with SB is independent self-management.

Disparities exist among race/ethnicity in the prevalence of SB worldwide (Atta et al., 2016). Hispanics/Latinos living in the United States have a higher prevalence of SB (3.80 per 10 000 live births) than non-Hispanic Whites (3.09) and non-Hispanic Blacks (2.73) (Canfield et al., 2014). Unfortunately, with a few exceptions (e.g. Betz et al., 2010; Castillo et al., 2017), diverse samples in the study of self-management in SB are atypical. Indeed, Whites make up the majority of samples in the study of self-management and SB (i.e., 85% or more; Sawin et al., 2021). Therefore, little is known about self-management among non-White participants or possible differences in self-management behaviours across demographic groups.

Self-management is 'an active daily and flexible process in which youth and their parents share responsibility and decision making for managing their condition, health, and well-being through a wide range of knowledge, attitudes, activities, and skills. The goal of this increasing responsibility is to develop skills needed for transition to adulthood and independent living' (Logan et al., 2020, p. 583; Sawin et al., 2009; Schilling et al., 2002). The process by which self-management develops includes knowledge and beliefs, self-regulation skills and abilities, and social facilitation as relevant correlates (Ryan & Sawin, 2009). Condition self-management includes activities and skills that prevent or manage complications (e.g., pressure injuries, bladder infections, and renal disease) and reduce the effects of condition severity. Behaviours that fall within the condition self-management domain require knowledge of medical regimen and action to complete care tasks (i.e. intermittent catheterization, bowel management, use of assistive devices, and keeping appointments). Independent living self-management includes lifestyle activities such as household (e.g., laundry and preparing meals) and community living tasks (e.g., planning meals and deciding to do groceries), managing finances, and arranging transportation. Identifying the rate of independence across these domains over time provides an assessment of the acquisition of self-management behaviours (i.e., trajectory of condition self-management and independent living self-management). Trajectories provide a way to monitor the successful development of self-management as well as identify targets for intervention.

Grounded in the Individual and Family Self-Management Theory (Ryan & Sawin, 2009), individual (demographic and condition) characteristics are often proposed to be correlates of the process of self-management and the behavioural outcomes (Sawin et al., 2021). Although youth with SB gradually acquire increasing responsibility for their own care, emerging adults with SB (22–23 years of age) lag

behind peers without SB in reaching developmental milestones including decision-making responsibility, educational and vocational achievement, financial independence, and independent living (<30% live independently; Holmbeck & Kritikos, 2022). It is important to study both self-management and independence over time to better understand factors that foster healthy AYA self-management in SB.

A useful instrument for the assessment of self-management behaviours is the Adolescent/Young Adult Self-Management and Independence Scale (AMIS-II), a validated measure for use in people with SB (Sawin et al., 2018). This measure captures the actual achievement of self-management behaviours, not an individual's capacity to perform the skills. The measure provides a total (i.e., overall) score and subscale scores for condition and independent living self-management.

Few studies have evaluated demographic factors associated with self-management. Past evidence suggests that older age is associated with higher levels of self-management (Sawin et al., 2021). Less is known about the relationship between race/ethnicity and self-management in SB, because a third of the literature omits reporting race and only 16% report ethnicity (Sawin et al., 2021). Only three studies with small samples (<100 participants) examined associations between race/ethnicity and self-management; none have found significant associations (Chowanadisai et al., 2013; Fremion et al., 2021; Ridosh et al., 2021). Although self-management did not differ by race/ethnicity, Chowanadisai et al. (2013) reported that the Hispanic participants had higher rates of bladder and bowel management complications (i.e., urinary incontinence rates, bladder accidents, and less satisfaction with bladder and bowel management). Another study found that non-Hispanic Black males experience more incontinence, but did not evaluate self-management behaviours (Schechter et al., 2015). Further assessment of self-management behaviours by race/ethnicity may determine if Hispanics and non-Hispanic Black males are at greater risk with respect to the nature of their self-management trajectory when compared with other race/ethnicities.

Knowledge of sex differences across self-management behaviours within SB is also limited. In a study identifying correlates of independent use of intermittent self-catheterization, male gender was associated with a higher rate of self-management behaviours (Castillo et al., 2017). Males may eventually engage in more self-management, given that they experience more challenges with continence than females (Schechter et al., 2015). However, adolescent females (i.e., <18 years old) have demonstrated more growth than males in condition self-management by taking on more responsibility for care (e.g., catheterization and medications; Kayle et al., 2020). Another study found that sex predicted independent living status (i.e., females were less likely to live with parents or in a supervised living environment) in youth 18 to 25 years old, but this study did not examine the independent living self-management behaviours assessed by the AMIS-II (Bellin et al., 2011).

Only three studies have used a longitudinal growth analysis approach in the study of self-management in SB. Two of these studies were from the same study cohort as the current study but in youth under 18 years of age and found two distinct groups using measures

of responsibility for care, namely, a low (flat) trajectory and a high-increasing (steep) trajectory; the latter was found for roughly two thirds of the sample. Higher skill mastery and lower self-management behaviours reported by parents, not gender, predicted group membership in a high-increasing trajectory for self-catheterization (Chu et al., 2022). Kayle et al. (2020) reported that females were 2.65 times more likely to be in the high-increasing medical responsibility group compared to males. Race/ethnicity and socioeconomic status assessed by the Hollingshead Index were not predictors of growth in medical responsibility (Kayle et al., 2020). In another study, and using a self-report, parallel version of the AMIS-II (Sawin et al., 2013), the total self-management score did increase over time in the study sample, which included 14- to 20-year-olds (Fremion et al., 2021). Demographic characteristics (e.g., sex, race/ethnicity, and insurance) were not associated with baseline self-management scores (Fremion et al., 2021); relations with trajectories were not assessed.

The current study will be the first to examine growth of self-management with the interview version of the AMIS-II and evaluate components of self-management. Generating one trajectory for each outcome (i.e., total, condition, and independent living), this study will examine growth of self-management and predictors of such growth. Building on past work, we will determine if young adult females (i.e., >18 years old) continue to demonstrate more growth of independence in self-management behaviours than males or if they do not differ at later ages. It will also establish whether race/ethnicity and income are important predictors of growth in self-management after youth are 18 years old.

This study aims to (a) determine if there is growth in self-management over time and (b) examine age, gender, race, ethnicity, and income in association with trajectories of self-management. Specifically, we hypothesize that self-management will increase over time and that growth in AMIS total, condition, and independent living scores will *depend* on respondent characteristics. That is, we believe that such trajectories will be higher (steeper) for respondents identifying as female (rather than male) and for those identifying as non-Hispanic White (relative to those identifying as Black or Hispanic/Latino).

## 2 | METHODS

Families were recruited to participate in a longitudinal study examining family, psychosocial, and neurocognitive functioning in youth with SB from four hospitals near Chicago and through a Midwest-based Spina Bifida Association (e.g., Devine, Holmbeck, et al., 2012). Inclusion criteria were as follows: (a) an SB diagnosis, (b) 8–15 years old, (c) can understand English or Spanish, (d) involvement of at least one main caregiver, and (e) lives within 300 miles of the study lab for home visit data collection. A total of 246 families were recruited, and 163 families agreed to participate. After initial consent, 21 families either declined to participate or could not be contacted and two families did not meet the inclusion criteria. Thus, at Time 1, the beginning of the longitudinal data collection, 140 families with children with SB

participated, including Hispanics ( $n = 42$ ). Participants who enrolled in the larger study did not differ from those who declined on type of SB, shunt status, or the number of shunt infections (Driscoll et al., 2018). In the sample of 140, youth were 52.9% White, 13.6% Black, 27.9% Hispanic, 1.4% Asian, and 4.3% multiracial. Of those who were identified as multiracial, three were White and Black; two were White and Hispanic; and one was White, Hispanic, and Asian. Slightly more females ( $n = 75$ , 53.6%) versus males ( $n = 65$ , 46.4%) participated. Over half of parents reported a family income of 50K or above (59.3%; 12 or 8.6% were missing data on income). The type of SB was 87.9% myelomeningocele, 77.9% had a shunt, and half had a lumbar lesion level (49.3%). Demographic details for the subsample examined in the current study are presented in Section 3.

### 2.1 | Sample description

Longitudinal data collections occurred every 2 years in the family home or in the youth's home, if living independently at later time points. The first time point (Time 1) included children 8 to 15 years of age and their parents, Time 2 included 10- to 17-year-olds and so on. About 25% of the sample youth reached 18 years of age at Time 3, 50% at Time 4, 75% at Time 5, and 100% at Time 6. Self-management was assessed with the AMIS-II for youth over 18 years of age; therefore, Times 3–6 were used for youth who completed the interview to examine the trajectory of self-management. Overall, the level of missing data on the AMIS-II at each time point corresponds roughly to the number of individuals who were ineligible to complete the assessments at a given time point (due to being <18 years old). Specifically, rates of missing data were 76.5% at Time 3, 52% at Time 4, 33.7% at Time 5 and 20.4% at Time 6. During the latter portion of Time 6, the data collection method for the interview changed from in-home to virtual sessions due to the COVID-19 pandemic. This study includes only those participants who completed the AMIS-II interview in-person during the home visit data collection before the pandemic began in March 2020. All participants with a minimum of one observation over the four data collection points were included. Thus, the sample included 99 unique participants and 214 total observations. The mean age of the first recorded observation was 19.98 ( $SD$  1.80). Although age rather than time point was used to examine predictors over time, mean ages for those who were >18 at each time point were as follows: Time 3 = 19.2; Time 4 = 20; Time 5 = 21.4; and Time 6 = 23.3.

### 2.2 | Procedures for data collection

Youth were interviewed during home visits conducted by trained undergraduate- and graduate-level research assistants. Demographic information was reported by parents (mothers and fathers) at the beginning of the study (Time 1). Informed consent from parents and assent from youth were obtained at Time 1, and adolescents and young adults (AYAs) >18 years old were consented as adults when

eligible beginning at Time 3. The longitudinal study was approved by university and hospital-based institutional review boards (IRBs). The AMIS-II interviews were audio-recorded by a research assistant. Participants were provided with a description of each item prior to the interview question. Follow-up questions were also used for clarification as described in the administration instructions.

## 2.3 | Measures

### 2.3.1 | Parent Demographic Questionnaire

The Parent Demographic Questionnaire was completed by both mothers and fathers. Questions about the child included the child's date of birth, sex, race, ethnicity, and family income. Exact age was used for the analysis (i.e., age was not rounded or truncated). The item for the child's race and ethnicity was combined (i.e., 'Your child's ethnicity/race'); possible responses were White, African-American, Hispanic, Asian, and other. If participants selected 'other', they were provided with space to write in a response. The race and ethnicity data were recoded to identify those participants who selected 'other' or were multiracial. If participants identified as multiracial including Hispanic (i.e., if participant reported White and Hispanic), they were included in the study as a Hispanic. Mother and father report of annual family income at Time 1 were significantly correlated ( $r = 0.920$ ); therefore, scores were averaged and recoded as dichotomous based on earning less than or greater than 50K.

### 2.3.2 | Adolescent/Young Adult Self-Management and Independence Scale (AMIS-II)

The AMIS-II interview was completed by AYA > 18 years old. The structured interview assesses the level of assistance required by the AYA to perform independent living skills and condition-related self-management. The interview includes 17 items (e.g., condition: knowledge; condition: complication prevention; self-management: ordering medication/supplies, making healthcare appointment; transportation; household skills; and community living skills) scored on a 7-point Likert scale from 1 to 7 [1 = *total assistance*: AYA does little or none of the activity less than 25% of the time; 2 = *maximal assistance/prompting*: AYA does the activity 25–49% of the time; 3 = *moderate assistance*: AYA does the activity 50–74% of the time; 4 = *minimal assistance/prompting*: AYA does the activity 75–90% of the time; 5 = *supervision*: AYA does the activity independently but needs supervision (90% or more independent); 6 = *modified independence*: AYA does the activity independently but has safety or time issues, or independent with use of assistive device; and 7 = *complete independence*: AYA does the activity independently 100% of the time; a score of 8 is assigned when item is 'not applicable']. If a score of 8 was recorded, the item was omitted from the subscale score. The AMIS-II total and subscales (condition self-management and independent living self-management; see Table 1 for items per subscale) were

calculated only if no more than two items were missing from the scales. An individual's subscale or total scores were based on the mean of all items that were not scored as 'not applicable' (Sawin et al., 2018). Sawin et al. (2018) provide psychometric evidence for the AMIS-II including stability over time [i.e., AYA report in a 2-week interval intraclass correlation coefficient (ICC) = 0.84, 95% confidence interval (CI) 0.71 to 0.92]. This measure was also validated in a subsample ( $n = 64$ ) from the larger longitudinal study and further described in Ridosh et al. (2021).

The responses to interview items were scored by two coders in this study to assess for scoring reliability; two research assistants independently scored the audio-recorded interviews. Reliability between coders using Pearson correlations at the item level were high. The lowest correlations were as follows:  $r_{\text{Time } 3} = 0.764$  for Item 3 (self-management of medications);  $r_{\text{Time } 4} = 0.670$  for Item 6 (condition: complication prevention); and  $r_{\text{Time } 4} = 0.657$  for Item 16 (advocacy). ICCs (e.g., inter-rater reliability between coders of the AMIS-II interviews) for total and subscales were also computed. Guidelines for interpreting ICCs were as follows: 0.90 = excellent; 0.80 = very good; and 0.70 = adequate (Kline, 2016, p. 92). ICCs were excellent ( $\geq 0.946$ ). Therefore, data for the AMIS-II were averaged across the two coders.

## 2.4 | Analyses

Preliminary analyses included screening all variables for outliers and skewness. An attrition analysis was conducted to assess differences between the 99 participants and the 41 who did not participate (see below for details on non-participants). Internal consistency reliability for AMIS-II total and subscales was assessed at each occasion.

**TABLE 1** AMIS-II subscale items

Condition self-management (7 items)	Independent living self-management (10 items)
1. Personal safety	4. Self-management: making healthcare appointment
2. Condition: knowledge	5. Self-management: ordering medication/supplies
3. Self-management: medication	7. Manages insurance
6. Condition: complication prevention	8. Money/finances: income
11. Accessibility	9. Money/finances: managing money
16. Advocacy	10. Transportation
17a. Family involvement in self-management	12. Household tasks
	13. Community living
	14. Social communication
	15. Problem solving

Participant characteristics are provided as counts with proportions for nominal and ordinal variables and as a mean and standard deviation (or median with range) for quantitative variables. To describe the sample, SB type, lesion level, presence of a shunt, and intelligence quotient (IQ) were reported. Age, sex, race, and income were included in the trajectory analyses. Linear mixed-effect models were used to measure AMIS-II scores (total, condition and independent living) over time. In these models, the explanatory variable of interest was elapsed time (age), which was centred at age 18. Interaction terms were included to assess when change in AMIS-II over time depended on participant demographics (i.e., sex, race, and income) and used a Sidak correction to control the Type 1 error rate. Further, because this study was longitudinal, participants could contribute multiple AMIS-II responses to the model. For this reason, random intercepts were allowed for each participant to account for their longitudinal (correlated) responses using a completely general (unstructured) covariance matrix. Random slopes were also allowed for each participant if inclusion improved model fit and parsimony as measured using Akaike's information criterion (AIC).<sup>1</sup> For all models, the denominator degrees of freedom were estimated using the method of Kenward and Roger (2009). All analyses were completed using R 4.1.0 (R Core Team, 2021) and the lmerTest package (v.1.1-28; Kunzetsova et al., 2017) as well as the ggplot2 package (v.3.3.3; Wickham, 2016).

### 3 | RESULTS

The current study sample ( $n = 99$ ) ranged in age from 18.2 to 27.0 years old (depending on the time point assessed). Roughly half were female (52.5%) and White (52.5%); 15.2% were Black, and about a third were Hispanic/Latino (32.3%). Eighty-seven AYAs (87.9%) had myelomeningocele. The lesion level was 31.3% sacral, 48.5% lumbar and 18.2% thoracic (level of lesion was mother-reported at Time 1 and verified by medical chart review; two reports were missing). A third of the sample earned less than 50K (32.3%; eight cases were missing report of family income) (see Table 2 for sample characteristics). Table 3 includes descriptive statistics for AMIS-II scale and subscales by time point in the study.

#### 3.1 | Preliminary analyses

All variables were examined for outliers. Only two participants identified as Asian; these cases were removed from the analysis because this would have produced a subsample that was too small for the race/ethnicity analyses. Subsequently, the AMIS-II items by coder were evaluated for skewness, which was determined by values greater than  $\pm 2$  (West et al., 1995). The highest skewness values were

**TABLE 2** Sample characteristics and study variables

Variables	Overall (N = 99)
Spina bifida type	
Myelomeningocele	87 (87.9%)
Not myelomeningocele	12 (12.1%)
Lesion level	
Sacral	31 (31.3%)
Lumbar	48 (48.5%)
Thoracic	18 (18.2%)
Missing	2 (2.0%)
Shunt present	
Yes	81 (81.8%)
No	17 (17.2%)
Missing	1 (1.0%)
Intelligence quotient	
Mean (SD)	84.7 (19.9)
Median [min, max]	84.0 [55.0, 137]
Missing	2 (2.0%)
Age at Time 1	
Mean (SD)	12.0 (2.29)
Median [min, max]	12.0 [8.00, 16.0]
Age at Time 3	
Mean (SD)	19.2 (0.719)
Median [min, max]	19.4 [18.2, 20.5]
Missing	76 (76.8%)
Age at Time 4	
Mean (SD)	20.0 (1.24)
Median [min, max]	19.8 [18.0, 22.1]
Missing	52 (52.5%)
Age at Time 5	
Mean (SD)	21.4 (1.87)
Median [min, max]	21.6 [18.0, 25.3]
Missing	34 (34.3%)
Age at Time 6	
Mean (SD)	23.3 (2.42)
Median [min, max]	23.5 [19.1, 27.0]
Missing	20 (20.2%)
Sex	
Male	47 (47.5%)
Female	52 (52.5%)
Race/ethnicity	
White	52 (52.5%)
Black	15 (15.2%)
Hispanic/Latino	32 (32.3%)
Income	
<50K	32 (32.3%)
≥50K	59 (59.6%)
Missing	8 (8.1%)

<sup>1</sup>This occurred for all models of the AMIS-II total self-management score except for the association between AMIS-II total and elapsed time stratified by race. For that model, the inclusion of a random slope produced unstable estimates and standard errors (poor convergence).

2.7 and 2.8 for Items 12 and 13, respectively. These items correspond to household skills and community living only at Time 3; most participants endorsed total assistance (i.e., participants at their first observation did little to none of the activity). All other items were not skewed (i.e., <2). No other skewness was detected at the item level for Time Points 4–6. No skewness was detected at the scale level for any time point. Thus, data transformations were not conducted.

Of the 41 enrolled who were not included in this study, 29 participants stopped participating in the study before they turned 18 years of age at their study visit(s) (i.e., did not complete the AMIS-II interview), 5 participated by only completing questionnaires and were not interviewed, 5 were interviewed only in an online format due to COVID-19 restrictions after 1 March 2020, and as noted earlier, 2 were of Asian background. For the attrition analyses, as expected, the included cohort was 2 years (95% CI –2.67 to –0.96;  $p < 0.001$ )

older than the participants without the outcomes of interest for this study but remained comparable on key demographic characteristics (sex, race, income, and lesion level; all  $p > 0.05$ ). Regarding the internal consistency reliability of the AMIS-II, the alphas were very high for both the total and subscale constructs (range:  $\alpha = 0.896$ – $0.956$ ), which are somewhat higher than the published results in the original psychometric paper (Sawin et al., 2018).

For all analyses, age was centred at 18 years old. The average intercepts and slopes for total, condition, and independent living self-management were significantly different from zero (all  $p < 0.05$ ). Although the variances for the random slopes within the total and independent living models were small ( $\sigma^2 = 0.01$  and  $\sigma^2 = 0.02$ , respectively), adding them improved model fit. For the condition self-management score, all models fit best when using only a random intercept (rather than both a random intercept and slope) term. At age

**TABLE 3** Descriptive statistics AMIS-II by time point

Variables	Time 3 (obs = 23)	Time 4 (obs = 47)	Time 5 (obs = 65)	Time 6 (obs = 79)
AMIS-II total scale	3.19 (1.45)	3.49 (1.41)	3.72 (1.32)	3.97 (1.43)
AMIS-II condition	3.88 (1.76)	4.10 (1.64)	4.12 (1.44)	4.36 (1.55)
AMIS-II independent living	2.72 (1.27)	3.07 (1.34)	3.44 (1.34)	3.70 (1.44)

Note: Means and standard deviations are reported by number of observations (obs) for each time point.

**TABLE 4** AMIS-II assessment

	N	AMIS-II					
		Total		Condition		Independent living	
		$\hat{\beta}$ (95% CI)	P	$\hat{\beta}$ (95% CI)	p	$\hat{\beta}$ (95% CI)	p
Age (per year increase)	99	0.12 (0.07 to 0.16)	<0.001	0.05 (0.01 to 0.09)	0.01	0.16 (0.11 to 0.23)	<0.001
Sex <sup>a</sup> : females vs. males	99	0.30 (–0.19 to 0.79)	0.23	0.16 (–0.42 to 0.74)	0.58	0.25 (–0.21 to 0.78)	0.28
Race/ethnicity <sup>a</sup>	99		0.02 <sup>b</sup>		0.02 <sup>b</sup>		0.01 <sup>b</sup>
Black vs. White <sup>c</sup>		0.27 (–0.59 to 1.13)	0.83	0.11 (–0.90 to 1.11)	0.99	0.48 (–0.33 to 1.29)	0.39
Hispanic/Latino vs. White <sup>c</sup>		–0.64 (–1.29 to 0.02)	0.06	–0.86 (–1.63 to –0.09)	0.02	–0.52 (–1.14 to 0.09)	0.12
Black vs. Hispanic/Latino <sup>c</sup>		0.91 (0.01 to 1.83)	0.053	0.96 (–0.11 to 2.04)	0.09	1.01 (0.14 to 1.87)	0.02
Income <sup>a</sup> : ≥50K vs. <50K	91	0.77 (0.24 to 1.28)	0.004	0.91 (0.31 to 1.51)	0.003	0.64 (0.14 to 1.14)	0.01
Age × sex interaction	99		0.18 <sup>b</sup>		0.01 <sup>b</sup>		0.84 <sup>b</sup>
Age   male		0.15 (0.09 to 0.21)	<0.001	0.11 (0.05 to 0.17)	<0.001	0.17 (0.09 to 0.24)	<0.001
Age   female		0.09 (0.03 to 0.15)	0.005	0.001 (–0.06 to 0.06)	0.96	0.16 (0.08 to 0.23)	<0.001
Age × race interaction	99		0.02 <sup>b</sup>		0.03 <sup>b</sup>		0.23 <sup>b</sup>
Age   White		0.10 (0.05 to 0.15)	<0.001	0.05 (–0.01 to 0.10)	0.08	0.16 (0.09 to 0.22)	<0.001
Age   Black		0.27 (0.15 to 0.39)	<0.001	0.21 (0.08 to 0.34)	0.001	0.28 (0.13 to 0.44)	<0.001
Age   Hispanic/Latino		0.08 (0.02 to 0.15)	0.01	0.01 (–0.07 to 0.08)	0.84	0.13 (0.04 to 0.22)	0.007
Age × income interaction	91		0.94 <sup>b</sup>		0.54 <sup>b</sup>		0.85 <sup>b</sup>
Age   <50K		0.12 (0.04 to 0.20)	0.005	0.08 (–0.001 to 0.16)	0.053	0.15 (0.05 to 0.25)	0.003
Age   ≥50K		0.12 (0.06 to 0.17)	<0.001	0.05 (–0.005 to 0.10)	0.08	0.16 (0.10 to 0.23)	<0.001

Note: N = number of participants used to compute the univariate estimates. Estimates for age are per year increase.

<sup>a</sup>Model conclusions are adjusted for elapsed time (age).

<sup>b</sup>Type III test of the fixed effect.

<sup>c</sup>Estimate is corrected for multiple pairwise comparisons using a Sidak correction.

18, most youth required at least moderate assistance for self-management overall. Based on a possible range of scores from 1 to 7, the average AMIS-II score was roughly 3 points (intercept = 3.26;  $SE = 0.13$ ; 95% CI 3.01 to 3.52) for the total scale, almost 4 points for the condition self-management subscale (intercept = 3.93;  $SE = 0.16$ ; 95% CI 3.61 to 4.25) and below 3 points for the independent living self-management subscale (intercept = 2.80;  $SE = 0.12$ ; 95% CI 2.55 to 3.05). An independent living score less than 3 points indicates that the individual requires maximal assistance/prompting in domains of independent living self-management. In our study, the AMIS-II total score increased by almost 1 point over 8 years (0.96 points; 0.12 points per year; i.e., slope = 0.12,  $SE = 0.02$ ;  $p < 0.001$ ). The condition self-management subscale increased about a half point (0.4 points; slope = 0.05,  $SE = 0.02$ ;  $p = 0.01$ ), and the independent living scale increased by slightly over 1 point (1.28) during the study (slope = 0.16,  $SE = 0.03$ ;  $p < 0.001$ ).

### 3.2 | Predictors of growth trajectories

Findings from linear mixed-effect models are reported by total and subscales (see Table 4). When considering participant characteristics, race and income (but not sex) were associated with the AMIS-II total score (all  $p < 0.05$ ). The association between age and the AMIS-II total score depended on race ( $p = 0.02$ ). That is, for every year increase in age, the AMIS-II total score increased by 0.10 (95% CI 0.05 to 0.15) points for White participants and increased by 0.08 (95% CI 0.02 to 0.15) for Hispanics/Latinos. However, for respondents who identified as Black, the AMIS-II total score increased by 0.27 for every year

increase in age (95% CI 0.15 to 0.39) or an increase of about 2 points over 8 years. This increase was sharper than the increase for Whites ( $p = 0.03$ ) as well as for those who identified as Hispanic/Latino ( $p = 0.02$ ) (see Figure 1 for differences in growth of total self-management by race/ethnicity).

The association between age and AMIS-II condition also depended on the race of the participant (interaction  $p = 0.03$ ). Those identifying as Black saw an increase of 0.21 in their condition score (95% CI 0.08 to 0.34,  $p = 0.001$ ) for every 1-year increase in age. Conversely, the slope was flatter for those identifying as White ( $\hat{\beta} = 0.05$ , 95% CI  $-0.01$  to 0.10) as well as for those identifying as Hispanic/Latino ( $\hat{\beta} = 0.01$ , 95% CI  $-0.07$  to 0.08). Figure 2 displays AMIS-II condition by race/ethnicity. Although growth in AMIS condition over time was comparable between those with high and low income (interaction  $p = 0.54$ ), participants with high income were on average about 0.91 (95% CI 0.31 to 1.51) points higher than those with low income regardless of age ( $p = 0.003$ ). Finally, the association between age and AMIS-II condition depended on sex (interaction  $p = 0.01$ ). For males, the trajectory was steeper ( $\hat{\beta} = 0.11$ , 95% CI 0.05 to 0.17;  $P < 0.001$ ) than for females ( $\hat{\beta} = 0.001$ , 95% CI  $-0.06$  to 0.06;  $p = 0.96$ ) (see Figure 3 for sex differences in trajectories for AMIS-II condition).

Regarding the independent living subscale, growth over time did not depend on sex (interaction  $p = 0.84$ ), and both sexes had comparable scores regardless of age ( $M_{diff} = 0.25$ , 95% CI  $-0.21$  to 0.78;  $p = 0.28$ ). However, findings for age and race were different from those reported for the AMIS-II condition and total self-management conclusions. For this outcome, individuals identifying as Black had comparable growth over time relative to those identifying as White or

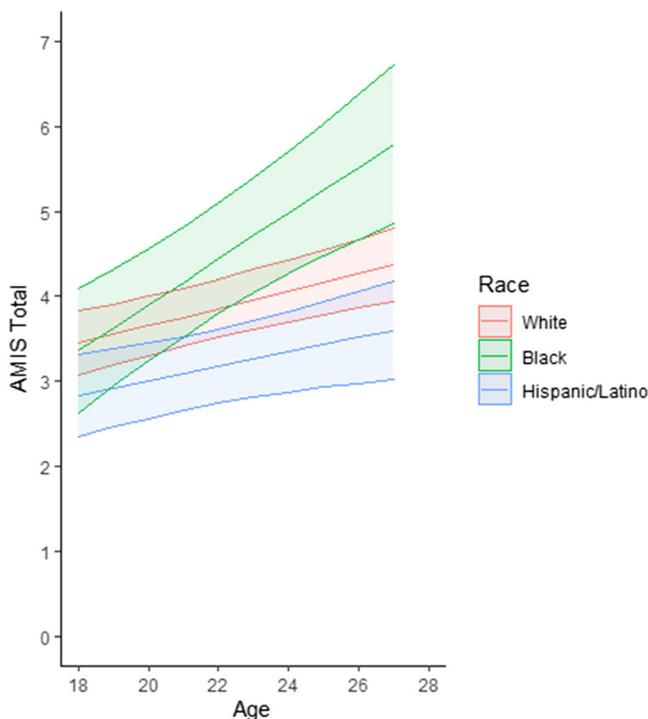


FIGURE 1 AMIS-II total: race by age trajectories

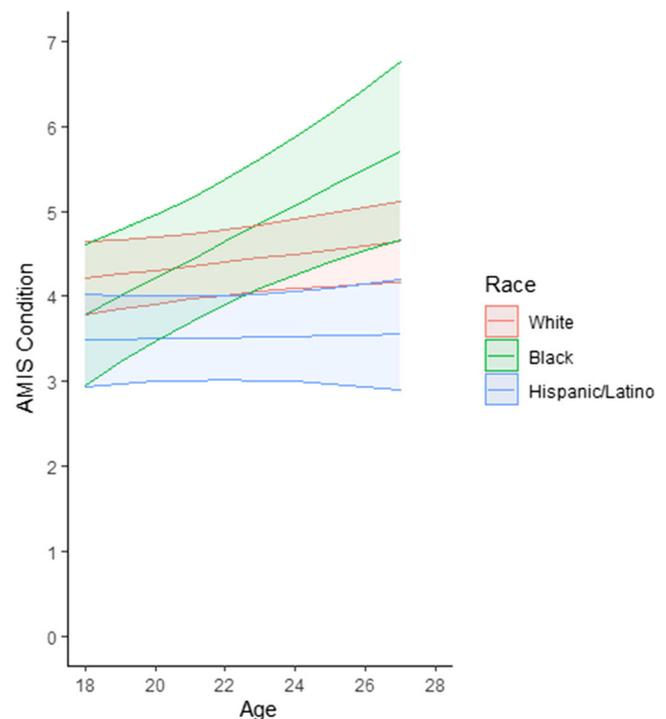
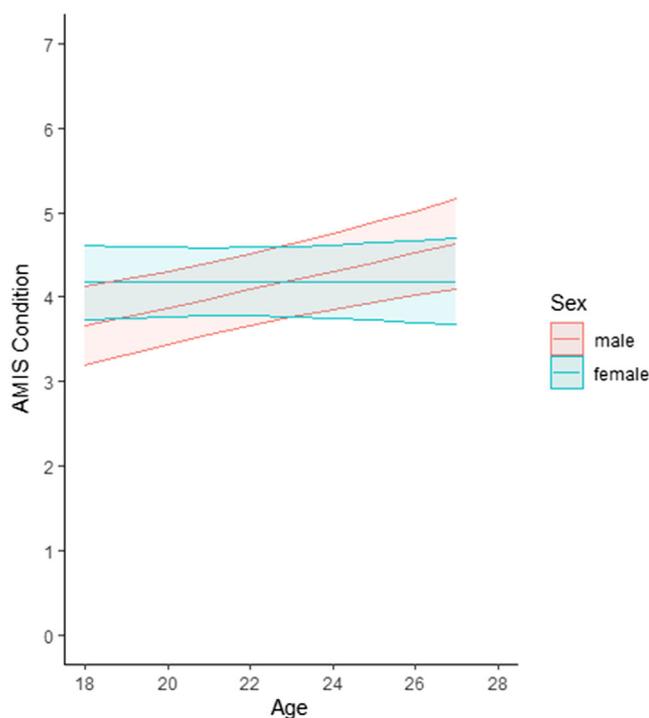


FIGURE 2 AMIS-II condition: race by age trajectories



**FIGURE 3** AMIS-II condition: sex by age trajectories

Hispanic (interaction  $p = 0.23$ ). Still, regardless of age, participants identifying as Black reported higher independent living scores relative to those identifying as Hispanic ( $M_{\text{diff}} = 1.01$ , 95% CI 0.14 to 1.87;  $p = 0.02$ ) but not relative to those identifying as White ( $M_{\text{diff}} = 0.48$ , 95% CI  $-0.33$  to 1.29;  $p = 0.39$ ). Finally, growth in AMIS independent living over time was also comparable between those with high and low income (interaction  $p = 0.85$ ), but participants with high income reported an average independent living score that was about 0.64 (95% CI 0.14 to 1.14) points higher than those with low income, regardless of age ( $p = 0.01$ ).

## 4 | DISCUSSION

The current study provides evidence of growth in self-management for youth over 18 years of age, and this growth also varied by demographic characteristics. Consistent with our hypothesis, self-management increases over time in early adulthood. The achievement of total self-management depends on race/ethnicity, whereas condition self-management depends on both sex and race/ethnicity. Further, contrary to our hypothesis, some groups that we expected to have less growth exhibited more growth (e.g., males and Blacks).

Regarding condition self-management, though no sex differences were demonstrated at age 18 (males 3.85 vs. females 4.01), males unexpectedly demonstrated change over time; females' scores remained relatively unchanged across this age range. Using a different self-management measure of shared responsibility for care in the same study cohort at earlier time points (a measure highly correlated with the AMIS-II; Ridosh et al., 2021), females under 18 demonstrated

more growth in self-management than males (Kayle et al., 2020). These findings over time demonstrate that females' growth may occur earlier than is the case for males, whereas males show later growth and appear to 'catch up'. Also, once females reach 18, their level of independence appears to plateau. Both sexes perform at a level of independence that continues to require minimal assistance/prompts to supervision (scores averaging between 4 and 5 on the AMIS-II). These scores and other assessments demonstrating increased independence skills and responsibility for care when youth were younger (8–17 years) suggest that continued parent involvement/caregiver assistance is needed to optimize outcomes, especially given evidence of decreased adherence to their medical regimen in many youth during this developmental period (Psihogios et al., 2015).

Contrary to our hypothesis, Black respondents demonstrated the most growth in self-management. Although this conclusion was not statistically significant for the independent living construct (interaction  $p = 0.23$ ), it was significant for the total self-management (interaction  $p = 0.02$ ) and condition self-management constructs (interaction  $p = 0.03$ ). For the total self-management score, Black respondents reported sharper growth relative to White respondents ( $p = 0.03$ ) as well as Hispanic/Latino respondents ( $p = 0.02$ ). Hispanics/Latinos fared worse than expected with little to no growth in total and condition self-management. Given findings from the National Spina Bifida Patient Registry (NSBPR) regarding poorer health outcomes for Blacks (i.e., less likely to exhibit bowel and urinary continence), the current results are concerning. Although it is desirable for most youth to reach higher levels of independence, the combination of these two sets of findings indicates that youth in this subgroup may have been granted a higher level of independence than is developmentally appropriate.

For Hispanics/Latinos, lack of growth in condition self-management is also concerning and may be attributed to a parents' higher perceptions of vulnerability in their children (Devine, Holbein, et al., 2012) resulting in more continued parent involvement in care (i.e., less AYA responsibility for care). From our analysis, we know *when* and the *rate* by which youth experience growth in self-management, not *how* Black or Hispanic/Latino families facilitate the transfer of self-management. Perhaps parents in families of these youth promote condition management, in preparation for independent living status in different ways than in other families. Further study of contextual and process factors, such as other sociodemographic factors or the family environment, may help explain these differences across ethnic/racial subgroups.

Higher income was related to better self-management in our study. Regardless of participants' age, the AMIS total score was about 0.77 units higher for high-income respondents than low-income respondents, but rate of growth in self-management did not depend on income. Importantly, income was collected at the beginning of the study when youth were 8–15 years old and reflects the family's income as reported by parents. Participants who earned lower income (<50K) started out at lower rating of total self-management and remained lower. Put another way, the rate of change (slope  $M_{\text{diff}} = 0.01$ ) was the same for both groups, so those in the low-

income group did not 'catch up'. In a study of sociodemographic risk conducted with the same sample when they were younger, a higher family income-to-needs ratio was associated with fewer lifetime number of urinary tract infections (Papadakis & Holmbeck, 2021). It is possible that the families with higher income have more resources for consistent access to supplies and are able to provide more support while youth remain at home. Continued attention to predictors of healthy self-management trajectories including social determinants of health must be considered to promote better health outcomes for individuals with SB.

#### 4.1 | Limitations and future research

The present study has a number of strengths as well as limitations. First, this was a longitudinal study, which included a larger number of Hispanics/Latinos than is typical. Also, the inclusion of multiple observations in this longitudinal study allowed us to examine the trajectories of self-management. However, although our study observed differences by race/ethnicity including steeper slopes of self-management for the Black participants, the Black participants made up the smallest proportion of the sample (15%). Also, although this study demonstrated differences across low versus high income on self-management, it will be important to select other sociodemographic factors in future studies to identify which may promote change in self-management over time. Our study collected race/ethnicity data as a combined category; therefore, when someone identified as Hispanic/Latino, their race was not considered because the majority of respondents did not select multiple categories (e.g., 4.3% multiracial in original sample). Finally, not all possible predictor variables were incorporated into the analyses and should be included in future studies (e.g., condition severity and neuropsychological functioning).

## 5 | CONCLUSIONS AND CLINICAL IMPLICATIONS

The present study contributes to our understanding of the trajectories of self-management as well as differences in growth by demographic variables (age, sex, and race/ethnicity). Overall, self-management in this community sample 18–27 years of age improves every year, but youth continue to need supervision; they have not yet achieved full self-management independence. These findings are important to consider with respect to clinical care, particularly as youth transition to adult-oriented care. Strategies for supervision or assistance in self-management remain important for emerging adults, because slow growth seems to occur in condition self-management in later years. Monitoring and reminder systems, whether through the use of technology or paper record/binders and checklists, can be used to facilitate independence to ensure completion of medical care regimens (e.g., bowel/bladder care, medication/supply ordering, and appointment making). Assessments of self-management in the clinic setting

can prompt clinicians to make concrete recommendations for assistive devices and to follow up on concerns, when responsibility for care is compromised. Future research must take into account differences in self-management across demographic groups, such as when identifying other predictors of self-management and related health outcomes.

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