

# Health risk behaviors among young adults with spina bifida

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This article is commented on by Sawin and Brei on pages 974–975 of this issue.

## PUBLICATION DATA

Accepted for publication 14th May 2012.

Published online 3rd September 2012.

## ABBREVIATION

HRB Health risk behavior

**AIM** Persons with spina bifida who adopt unhealthy lifestyles could be at increased risk of adverse health outcomes because the presence of spina bifida may magnify this risk. We estimated overall and age-specific prevalence of selected health risk behaviors (HRBs) in young people with spina bifida and examined the association between HRBs and depression.

**METHOD** We performed analyses on data obtained from individuals with spina bifida ( $n=130$ ; mean age 23y SD 4y 5mo; 64 males, 66 females; 64% lumbosacral lesion; 77% with shunt) who participated in a population-based survey conducted by the Arkansas Spinal Cord Commission in 2005.

**RESULTS** Compared with national estimates, young people with spina bifida tend to eat less healthy diets, do less exercise, and engage in more sedentary activities. Respondents were less likely to use substances (alcohol, tobacco, illegal drugs), which peaked among 25 to 31 year olds. About 90% saw a doctor in the previous year. Nearly one half reported mild or major depressive symptoms. In the logistic regression analysis after controlling for potential confounders (age, sex, ethnic group, education, employment, marital status, living arrangement, level of lesion, presence of shunt, mobility, self-rated health and healthcare utilization), major depressive symptoms were associated with current alcohol drinking (adjusted odds ratio: 4.74; 95% CI 1.18–19.04).

**INTERPRETATION** Young adults with spina bifida exhibit unhealthy behaviors that continue into their late 20s. The findings highlight the need to increase awareness of their health risk profiles in the spina bifida community and show opportunities for mental health and health risk screening and counseling by healthcare providers.

Individuals with spina bifida live longer now than ever before because of advances in medical science<sup>1</sup> and at least 75% of children born with a spina bifida can be expected to reach early adulthood.<sup>2</sup> The growth of this adult population has stimulated interest in their health and well-being<sup>1</sup> but we know relatively little about their health risk behaviors (HRBs) and emotional wellbeing.<sup>3</sup> Recent studies suggest that adolescents with a chronic condition are as likely or more likely to engage in risky behaviors than their healthy peers.<sup>4–6</sup> Persons with spina bifida who adopt unhealthy lifestyles could be at increased risk of adverse health outcomes because the presence of spina bifida may magnify this risk.<sup>4</sup>

Despite the growing body of literature on health and risky behaviors among adolescents, relevant research among young adults has received less attention. The contextual influences that shape risky behaviors, health outcomes and access to healthcare generally change at the transitional period of young adulthood during which young adults fare worse than adolescents in many areas such as injury and substance use.<sup>7</sup> Better understanding of how health and risky behaviors change with age has important ramifications for the timely delivery of age-appropriate services.

Studies on adolescents show that anxiety and depressive disorders are associated with risky behaviors.<sup>8,9</sup> Since young persons with spina bifida are at greater risk of depressed mood, low self-worth and suicidal ideation when compared with comparison individuals who are able-bodied,<sup>10</sup> exploring the relationship between depression and HRBs may highlight the need for more intentional screening and monitoring of mental health and HRBs.

A few studies that focused on unhealthy lifestyles among individuals with developmental disabilities have reported that adolescents with developmental disabilities including spina bifida<sup>11</sup> and young adults with developmental disabilities such as cerebral palsy and mental retardation<sup>\*12</sup> are more likely to engage in sedentary lifestyles and poor diets and less likely to drink alcohol, use illicit drugs or smoke when compared with peers without developmental disabilities. Although some studies have addressed perceived health or health-related quality of life among young adults with spina bifida,<sup>13</sup> there are no population-based studies that examine HRBs in this group. Therefore, our study had three objectives: (1) to estimate the

\* UK usage: learning disability

prevalence of certain HRBs among young adults with spina bifida; (2) to characterize the distributions of HRBs by age and compare them with similar aged adults from the general population; and (3) to examine the association between HRBs and depression.

## METHOD

### Participants

The data for current analyses were obtained from a 2005 state-wide survey conducted by the Arkansas Spinal Cord Commission (ASCC) to assess the development of secondary conditions among young individuals with spina bifida. With funding from the Centers for Disease Control and Prevention, the survey was targeted at individuals aged 12 to 31 years with spina bifida who were registered in the ASCC registry. The questionnaire was developed at the University of Arkansas for Medical Sciences (UAMS) and ethical approval for the study was obtained from its institutional review board. Trained case managers conducted face-to-face interviews at the home of individuals with spina bifida. After the interview, those aged 16 years or older were also asked privately to complete a self-administered supplemental questionnaire on substance use and sexual behaviors. Written informed consent was collected from all participants aged 18 years or older. For individuals under 18 years of age, parental consent and participant's assent were obtained. Given that the current study involved substance abuse, the analyses were restricted to individuals aged 16 years or older.

### Variables

Sociodemographic characteristics analyzed were age, sex, race, education, employment, marital status, and living arrangement (Table I). Health-related conditions comprised level of lesion, history of shunt, mobility, bowel and urinary incontinence, depression and health self-rating.

Symptoms of depression were assessed and scored using a 20-item questionnaire of the Center for Epidemiological Studies Depression Scale (CES-D).<sup>14</sup> CES-D scores of 16 to 26 are considered indicative of experiencing mild depressive symptoms and scores of 27 or more indicate major depressive symptoms.<sup>15</sup> We obtained a Cronbach's alpha coefficient of 0.88, indicating a good internal consistency of the scale.

Health-related behaviors were selected among the Leading Health Indicators for Healthy People 2020:<sup>16</sup> physical activity (exercise, watching television); dietary habits; substance abuse (cigarette smoking, alcohol drinking, illegal drug use), and healthcare utilization (Table II). Appendix A shows the questions related to these behaviors from the 2005 ASCC survey and describes how the responses were categorized to identify HRBs.

### Statistical analysis

We estimated the overall prevalence of each HRB and characterized its age distribution. We examined the trends of prevalence of individual HRBs across age groups by the Cochran–Armitage test. We also compared the prevalence of

## What this paper adds

- In young adults with spina bifida, substance use peaks in their late 20s.
- Nearly half had mild or major depressive symptoms.
- Nearly 90% had a doctor visit in the past year, offering opportunities for screening and counseling for health risk behaviors and depression.

HRBs among respondents with national estimates for peers in the general population obtained from the 2005 Behavioral Risk Factor Surveillance System Survey,<sup>17</sup> the 2005 Youth Risk Behavior Surveillance – United States,<sup>18</sup> and the 2005 National Survey on Drug Use and Health: national findings<sup>19</sup> using the  $\chi^2$  goodness-of-fit test. We conducted multivariable logistic regression to model HRBs by age after adjusting for covariates that were differentially distributed among age groups. The logistic model parameter represents an odds ratio, which is an approximation to the relative risk under rare disease assumption.<sup>20</sup> Separate logistic regression models were run to examine the association between depression and individual HRBs, controlling for potential confounders (age, sex, ethnic group, education, employment, marital status, living arrangement, level of lesion, presence of shunt, mobility, self-rated health and healthcare utilization) that are associated with depression and HRBs found in the literature. We conducted regression diagnostics to check for model fitness and multicollinearity between independent variables. We used SAS statistical software (version 9.3; SAS Institute, Cary, North Carolina, USA) for all analyses. Statistical significance was assessed at the  $p < 0.05$  level and all tests were two-sided.

## RESULTS

A total of 153 individuals with spina bifida aged 12 to 31 years participated in the face-to-face interviews, a completion rate of 75% (10% refused the interview, 8% were unreachable, 5% had severe cognitive limitations<sup>21</sup> and 2% were deceased). For the current study, we focused on 130 individuals (64 males, 66 females) who were 16 years or older and completed the supplemental questionnaire on substance abuse. To validate the population-based nature of our sample, we applied a previously estimated crude prevalence of spina bifida (3.07 per 10 000 population aged 0–19y; 95% CI 2.96–3.17)<sup>22</sup> to the 2005 population of Arkansas aged 15 to 29 years ( $n=590\ 333$ ). The expected number of people with spina bifida aged 15 to 29 years in 2005 was 181 (95% CI 174–187), which was comparable with the number in our overall sample plus non-respondents. The mean age of the participants was 23 years (SD 4y 5mo). The demographic characteristics and health-related conditions of participants are presented in Table I. The distributions of participants by these characteristics did not differ significantly among three age groups (16–19y, 20–24y, 25–31y), except for marital status, living arrangement, bowel incontinence and history of shunt surgery ( $p < 0.05$ ). There were no sex differences in the distributions of HRBs (data not shown).

### Physical activity and diet

A majority of respondents reported neither eating healthy food regularly nor engaging in regular physical activity but reported watching television for 3 or more hours/day, independent of

**Table I:** Characteristics of young adults with spina bifida in Arkansas in 2005 (*n*=130)

Characteristic	<i>n</i> (%) <sup>a</sup>
Age at interview (y)	
16–19	35 (27)
20–24	38 (29)
25–31	57 (44)
Sex	
Male	64 (49)
Female	66 (51)
Ethnic group	
White non-Hispanic	104 (80)
Black non-Hispanic	21 (16)
Other	4 (3)
Highest level of education	
High school/general education development or less <sup>b</sup>	103 (79)
Greater than high school	26 (20)
Employment	
Competitive	21 (16)
Non-competitive	17 (13)
No job	89 (69)
Marital status	
Married/co-inhabiting with a partner	14 (11)
Divorced/separated	2 (2)
Single	112 (88)
Living arrangement	
Living with family with the need of family assistance	56 (43)
Living independently in family house with minimal assistance	31 (24)
Not living with family	41 (32)
Level of lesion	
Thoracic	47 (36)
Lumbar	71 (55)
Sacral	12 (9)
Ambulatory status	
Non-ambulatory (full-time wheelchair use)	62 (48)
Ambulatory	63 (49)
Bowel incontinence <sup>c</sup>	
Frequently	39 (30)
Occasionally	29 (22)
Rare or none	59 (45)
Urinary incontinence <sup>d</sup>	
Frequently	44 (34)
Occasionally	29 (22)
Rare or none	54 (42)
Shunt surgery	
No shunt	27 (21)
Shunt with no history of revision	20 (15)
Shunt with history of revision	80 (62)
Depressive symptoms <sup>e</sup>	62 (48)
Normal (CES-D score <16)	66 (52)
Mild (CES-D score 16–26)	40 (31)
Major (CES-D score >26)	22 (17)
Self-rating of general health	
Good/very good	94 (72)
Poor/fair	36 (28)

<sup>a</sup>Percentage may not add up to 100% due to missing values.

<sup>b</sup>Only 3 stated middle school as highest level of education.

<sup>c</sup>Categorized as frequently (usually daily, 3–4 times per week, 1–2 times per week), occasionally (3–4 times per month, 1–2 times per month), rare/none (less than once per month, 3–4 times per year, none).

<sup>d</sup>Categorized as rare/none (rarely or never, dampness in underwear [ $<1$ /month]), occasionally (only at night,  $<1$ /week), frequently (at least 1/week, daily).

<sup>e</sup>Quantified by the Center for Epidemiological Studies Depression (CES-D) scale (CES-D score  $\geq 16$  means presence of depressive symptoms).<sup>14</sup>

age (Table II). The prevalence of self-reported overweight increased significantly with age. Young adults in their late 20s were three times as likely to report being overweight as those in their late teens in multivariable analysis.

### Substance abuse

Among respondents, cigarette smoking (28%) and alcohol drinking (28%) were more frequently reported than behaviors such as binge drinking (15%) and lifetime illegal drug use (18%). Among illegal drug users, marijuana, pain pills (aspirin, acetaminophen [paracetamol], hydrocodone, oxycodone) and anti-anxiety drugs (alprazolam) were most frequently reported. Substance abuse (alcohol/tobacco/illegal drug use) was highest among respondents aged 25 to 31 years. The prevalence of current alcohol drinking and history of illegal drug use increased significantly with age. After controlling for confounders, the odds of reporting illicit drug use among respondents in their late 20s were nearly 10 times that among those in their late teens.

### Depression and self-rated health

About half of the respondents experienced mild or major depressive symptoms (Table I), with no significant change across age groups. Self-rated poor health started high in late teen years (20% reported fair–poor health) and continued to climb through young adulthood (32% reported fair–poor health) although the trend was not statistically significant. Multivariable logistic regression showed that individuals with major depressive symptoms were 4.7 times as likely to report drinking alcohol as individuals without major depressive symptoms (Table III). No other independent factors in the same model were associated with alcohol abuse except level of education where those with education level of high school or less were less likely to drink alcohol than those with education greater than high school.

### Comparison of HRBs and depression among respondents with the general population

About 22% of 18 to 24 year olds in the 2005 Arkansas general population did not exercise during the past month<sup>17</sup> compared with 74% of respondents who did not engage in regular physical activity ( $p<0.001$ ). The proportion of respondents who reported not eating whole grains/fruits/vegetables regularly was 75% compared with 12% among 18 to 24 year olds from the general population who did not consume at least a daily serving of fruits/vegetables<sup>17</sup> ( $p<0.001$ ). About 83% of late teen respondents watched television for 3 or more hour/day compared with 39% among Arkansas high school students<sup>18</sup> ( $p<0.001$ ). Overall and age-specific, the prevalence of substance abuse among participants was lower than that reported for the USA general population.<sup>19</sup> The prevalence of past month alcohol drinking among respondents (28%) was lower than the national estimate for 16 to 29 year olds (57%) ( $p<0.001$ ). The prevalence of past month tobacco smoking among respondents (28%) was lower than the national estimate for 16 to 29 year olds (35%) ( $p=0.08$ ). Similarly, lifetime

**Table II:** Overall and age-specific prevalence of health risk behaviors and multivariable analysis among young adults with spina bifida in Arkansas in 2005

Health risk behavior	Total P (%)	Bivariate analysis			Trend <sup>b</sup> <i>p</i> value	Logistic regression <sup>a</sup>	
		16–19y	20–24y	25–31y		20–24y	25–31y
		<i>n</i> P(%)	<i>n</i> P(%)	<i>n</i> P(%)		aOR (95% CI)	aOR (95% CI)
<b>Physical activity and diet</b>							
No exercise in the past 30d	96 (74)	27 (77)	27 (71)	42 (75)	0.88	0.9 (0.3–2.8)	1.0 (0.3–3.2)
No stretching exercises for 3 times/week	105 (81)	28 (80)	33 (87)	44 (80)	0.91	1.4 (0.4–5.5)	1.0 (0.3–3.4)
No exercise for 20 min for 3 times/week	105 (81)	27 (79)	33 (87)	45 (80)	0.98	1.3 (0.3–4.8)	0.8 (0.2–2.8)
No supervised exercise (at gym/fitness class)	120 (92)	32 (91)	37 (100)	51 (91)	0.76	n/a	n/a
No fun physical activities (like walking, swimming, rolling)	92 (71)	23 (66)	31 (82)	38 (68)	0.99	2.2 (0.7–7.0)	1.2 (0.4–3.4)
Did not eat whole grains/raw fruits/vegetables often/regularly	97 (75)	26 (74)	27 (71)	44 (80)	0.48	0.7 (0.2–2.2)	1.4 (0.4–4.5)
Did not eat healthy food often/regularly	97 (75)	29 (83)	26 (68)	42 (75)	0.49	0.4 (0.1–1.3)	0.6 (0.2–1.9)
Watched television ≥3h	108 (83)	29 (83)	32 (84)	47 (84)	0.90	1.1 (0.3–4.3)	1.4 (0.4–5.7)
<b>Substance use</b>							
Current alcohol drinking	36 (28)	5 (15)	12 (32)	19 (35)	0.05	2.3 (0.6–8.5)	1.7 (0.5–6.3)
Current binge drinking	19 (15)	3 (10)	4 (11)	12 (22)	0.09	0.6 (0.1–3.4)	1.1 (0.2–5.7)
Current cigarette smoking	36 (28)	6 (19)	11 (30)	19 (35)	0.13	1.3 (0.4–4.7)	1.1 (0.3–3.9)
Lifetime illicit drug abuse	23 (18)	1 (3)	7 (19)	15 (28)	<0.01	5.1 (0.6–47.6)	9.8 (1.1–88.8)
<b>Healthcare utilization</b>							
Not seen a doctor in the past year	14 (11)	2 (6)	5 (13)	7 (13)	0.60	1.4 (0.2–9.9)	1.3 (0.2–8.9)
<b>Other</b>							
Self-reported overweight	64 (49)	11 (31)	18 (47)	35 (61)	0.01	1.5 (0.5–4.4)	3.1 (1.1–8.8)

<sup>a</sup>Young adults in their late teens (aged 16–19y) were treated as the referent group, after controlling for marital status, living arrangement, bowel incontinence, and shunt surgery which were differentially distributed across three age groups.

<sup>b</sup>Cochran–Armitage test for trend. P(%)=prevalence; aOR=adjusted odds ratio; n/a=not available due to quasi-complete separation of data points detected.

**Table III:** Bivariate and multivariable analysis to examine association between individual health risk behaviors and depressive symptoms among young adults with spina bifida in Arkansas in 2005

Health risk behavior	Bivariate analysis			$\chi^2$ <i>p</i> value	Logistic regression <sup>a</sup>	
	Normal	Minor depression	Major depression		Minor depression	Major depression
	<i>n</i> P(%)	<i>n</i> P(%)	<i>n</i> P(%)		aOR (95% CI)	aOR (95% CI)
<b>Physical activity and diet</b>						
No exercise in the past 30d	49 (74)	30 (75)	17 (77)	0.96	1.1 (0.4–3.0)	0.7 (0.2–2.7)
No stretching exercises for 3 times/week	54 (82)	31 (80)	19 (86)	0.80	1.1 (0.4–3.5)	0.5 (0.1–2.6)
No exercise for 20 min for 3 times/week	55 (85)	32 (80)	17 (77)	0.69	1.7 (0.5–5.5)	1.4 (0.3–6.0)
No supervised exercise (at gym/fitness class)	62 (94)	37 (95)	20 (91)	0.78 <sup>b</sup>	n/a	n/a
No fun physical activities (like walking, swimming, rolling)	45 (68)	31 (78)	15 (68)	0.56	0.9 (0.3–2.5)	0.9 (0.2–3.1)
Did not eat whole grains/raw fruits/vegetables often/regularly	51 (79)	29 (73)	16 (73)	0.74	1.9 (0.7–5.6)	1.6 (0.4–5.9)
Did not eat healthy food often/regularly	49 (74)	33 (83)	14 (64)	0.26	0.5 (0.1–1.6)	1.9 (0.5–7.3)
Watched TV ≥3h	54 (82)	33 (83)	20 (91)	0.59	0.7 (0.2–2.3)	2.8 (0.4–18.0)
<b>Substance use</b>						
Current alcohol drinking	18 (28)	8 (21)	10 (48)	0.08	1.3 (0.4–4.1)	4.7 (1.2–19.0)
Current binge drinking	8 (13)	5 (13)	6 (29)	0.19	1.9 (0.4–8.7)	3.1 (0.6–15.4)
Current cigarette smoking	19 (29)	7 (18)	10 (48)	0.06	0.4 (0.1–1.5)	1.7 (0.4–6.5)
Illicit drug ever used in lifetime	12 (19)	6 (15)	5 (24)	0.72	0.7 (0.2–2.8)	1.2 (0.2–5.8)
<b>Healthcare utilization</b>						
Not seen a doctor in the past year	7 (11)	4 (11)	2 (9)	0.99 <sup>b</sup>	n/a	n/a

<sup>a</sup>No depression/depressive symptoms' was treated as the reference group, after controlling for sociodemographics (age at interview, sex, race/ethnicity, education level, marital status, living with family or not, employment), degree of spina bifida severity (level of lesion, presence of shunt, mobility), self-rated health and healthcare utilization that are potentially associated with depression and health risk behaviors in the literature.

<sup>b</sup>*p* value from Fisher's exact test. P(%)=prevalence; aOR=adjusted odds ratio; n/a=not available due to quasi-complete separation of data points detected.

marijuana use (3%) was lower among late adolescence respondents than the national estimate for early adolescence 12 to 17 year olds (17%) ( $p=0.02$ ). The prevalence of depressive symptoms among respondents (48%) was higher than the national estimate of current depression (within 2wks preceding the survey) among 18 to 34 year olds in the general population (10%)<sup>19</sup> ( $p<0.01$ ).

## DISCUSSION

Our study is the first population-based study to examine HRBs among young adults with spina bifida. We observed that a significant proportion of young adults with spina bifida have led unhealthy lifestyles and engaged in one or more risky behaviors. Alcohol abuse was positively associated with major depression. Depression and low self-rated health were highly prevalent. Compared with similar aged adults in the general population, young people with spina bifida tend to eat less healthy diets, do less exercise and engage more in sedentary activities. Also, young people with spina bifida were less likely to abuse tobacco, alcohol and illicit drugs, and when they did, it was at later ages. Nearly 90% of the study participants saw a doctor in the past year indicating a greater opportunity for screening and monitoring of mental health and HRBs. Webb<sup>23</sup> has pointed out that the general healthcare needs of adults with spina bifida (including health risk screening and counseling) are sometimes overlooked because so much emphasis is placed on spina bifida specific care.

That significant proportions of respondents were not engaged in any form of regular physical activity and spend time in sedentary activity may indicate challenges being encountered by young people with spina bifida for access to physical and leisure activities. These challenges may include the lack of facilities adaptive for physical activities of the spina bifida population, transportation issues accessing available facilities and difficulties obtaining personal assistance to engage in these activities.<sup>11,24</sup> Attitudinal and motivational factors<sup>25</sup> and medical contraindications may also play a role in the lack of physical activity. Our observation of poor dietary habits among respondents is consistent with a Canadian study of adolescents with physical disabilities that reported a lower likelihood of eating fresh produce but a higher likelihood of eating high-fat foods in comparison with a national sample.<sup>11</sup> Poor dietary habits and low levels of regular physical activity may partly explain high prevalence of being overweight reported by respondents. These observations are important because limited physical activity and poor dietary habits, which cause obesity, are modifiable and obesity can be reduced, if not entirely prevented.<sup>26</sup> Part of good childcare should include early efforts with family engagement to encourage physical activity and healthy eating to prevent obesity in this population.

The observation of overall and age-specific prevalence of substance abuse among respondents which was lower than national estimates<sup>19</sup> is in agreement with other studies.<sup>11,12</sup> The low level of engagement of smoking, alcohol and illicit drugs among individuals with spina bifida may be partially explained by the high level of parental/family supervision in

their social activities<sup>27</sup> and/or lack of opportunity resulting from mobility and financial constraints on exposure to the social environment that could potentially influence negative behaviors.<sup>11,12</sup> Although the prevalence of substance abuse among individuals with spina bifida may be low, that participants with major depression were more likely to drink alcohol is a cause for concern because it can lead to worsening of adverse health and social outcomes. Previous studies among young people in the general population have shown that substance use and risky sexual behaviors are often associated with anxiety and depressive disorders.<sup>8,9</sup> As nearly half of young respondents were experiencing depression comparable with other clinic- or community-based studies,<sup>10,28</sup> screening and counseling on both mental health disorders and substance abuse should be a priority for healthcare providers in both primary and specialty care settings.

It is noteworthy that the mode of substance abuse was highest among individuals with spina bifida in their late 20s, though only illegal drug abuse and alcohol drinking showed significant positive trends possibly because of the limited sample size. By contrast, the risk profile among the general population shows a peak in the early 20s.<sup>7</sup> Young individuals with spina bifida may be experiencing an especially prolonged transition to adult roles and responsibilities with diminished parental supervision and the weakening of the safety net that normally supports adolescents and younger children such as school and quality healthcare, which are important contextual factors associated with unhealthy living and risky behaviors.<sup>7</sup> Though adolescents with spina bifida are capable of high levels of independent functioning across multiple domains, they are at risk of delays in development of self-management and independence,<sup>29</sup> and are therefore less likely to move into marriage, parenthood and employment at the same rates or age as typical young adults. This was reflected in our study where the majority of respondents in their late 20s was not employed (69%), remained unmarried (88%) and still lived with families for their assistance (43%).

Overall delays in social maturation and independence and the lack of traditional supportive systems may explain the late onset of substance abuse among young adults with spina bifida. As with the general population,<sup>8,9</sup> the presence of poor health and depression also add to the risk of substance abuse. The loss of the traditional supports of education and child-specific healthcare,<sup>7</sup> plus the ambivalence of being dependent on family,<sup>30</sup> puts the young adult with spina bifida in a vulnerable position. Feeling less powerful in mastering one's life and feeling less healthy may magnify depression and threaten the development of independence and self-management of health. Health status is already compromised and slowly starts to decline (data not shown) with accumulation of physical symptoms over time. This may lead to a fatalistic life view<sup>5</sup> which could be reflected in unhealthy behaviors such as tobacco, drug and alcohol abuse among respondents in their late 20s. Declining health status may also decrease motivation to seek out intimate relationships like marriage. This health status, along with loss of public insurance, transportation challenges and depressive symptoms, may also limit the pursuit of regular

employment. To counteract these trends, interventions such as peer support, group counseling and specific skills training may be necessary to help young adults with spina bifida to maintain a more positive and hopeful outlook. Ongoing healthcare is also needed to monitor for specific organ-system progression (e.g. renal function, shoulder girdle overuse).

The strength of our study is that it is based on a statewide population with spina bifida rather than a clinic sample and that it has valuable information to examine unhealthy lifestyles among young adults with spina bifida in their late teens and 20s. However, it has certain limitations. First, the study was cross-sectional and causality could not be assessed. Second, since the ASCC state-based registry is service-oriented, there may be individuals who remained unregistered, although we believe most young people with spina bifida were captured by the system, based on our calculation of the expected number of individuals with spina bifida in Arkansas. Even among those registered, 25% did not complete the interview for a number of reasons. Third, a direct comparison group of healthy peers was not feasible because the sample was obtained from a spinal cord disability registry. Fourth, in addition to recall bias, self-reporting of conditions may change over time because of the maturity of those reporting, e.g. 28-year-olds may report their weight more accurately or honestly than 17-year-olds. Fifth, the sensitive nature of questions such as illicit drug abuse may underestimate usage. Sixth, due to survey exclusion criteria, the results may not be generalizable to those with spina bifida who have a severe cognitive limitation. Lastly, since this supplementary study on HRBs was part of a large survey, only a limited number of questions on HRBs were asked. For example, a distinction between experimental versus habitual abuse of substances was not made. A larger population-based study

more focused on HRBs and predisposing psychosocial and environmental factors, could answer these additional questions.

In summary, a notable proportion of young individuals with spina bifida exhibit unhealthy behaviors that continue into their late 20s. To promote healthy behaviors and quality of life in this population, it is necessary to increase awareness of their health risk profile among people with spina bifida and their caregivers. Although substance use is less common than expected for their age among young people with spina bifida, the presence of low self-rated health, depression and its relationship with certain HRBs warrants continued monitoring of physical and mental health by healthcare providers. Discussions should also begin during childhood with a focus on helping the child work toward mastering a fully independent life such as educational and vocational achievement, independent living, healthy lifestyle choices and social participation. Finally, promoting access to accommodative social support and preventive services would increase the chances of successful adult living for individuals with spina bifida.

## ACKNOWLEDGEMENTS

We thank Drs Michael Fox and Rodolfo Valdez for their reviews of this manuscript and the staff of the Arkansas Spinal Cord Commission (ASCC) and the University of Arkansas for Medical Sciences (UAMS) for their devoted engagement in the development and design of the survey, data collection and data management. We also extend our gratitude to the participants with spina bifida and their families whose selfless participation in this project made the current analysis possible. The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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## APPENDIX-A: The 2005 Arkansas Spinal Cord Commission survey questions

Health risk factor	Questionnaire item	Response in questionnaire	Health risk behavior	Response category
Healthcare utilization	When was the last time you were seen by your doctor?	<ol style="list-style-type: none"> <li>1. Less than a month ago</li> <li>2. Between 1mo and 1y ago</li> <li>3. More than 1y but &lt;2y ago</li> <li>4. More than 2y but &lt;3y ago</li> <li>5. More than 3y ago</li> </ol>	Not seen a doctor in the past year	Yes=response 3-5 No=response 1-2
Physical activity	During the past 30d, did you exercise to lose weight or to keep from gaining weight?	<ol style="list-style-type: none"> <li>1. Yes</li> <li>0. No</li> </ol>	No exercise in the past month	Yes= response 0 No= response 1
	Do stretching exercises at least 3 times a week	<ol style="list-style-type: none"> <li>1. Never</li> <li>2. Sometimes</li> <li>3. Often</li> <li>4. Regularly</li> </ol>	No stretching exercise	Yes=response 1-2 No=response 3-4
	Exercise for about 20 min at least 3 times a week	<ol style="list-style-type: none"> <li>1. Never</li> <li>2. Sometimes</li> <li>3. Often</li> <li>4. Regularly</li> </ol>	No exercise for 20 minutes	Yes=response 1-2 No=response 3-4
	Do supervised exercise (like going to gym, physical education or fitness class)	<ol style="list-style-type: none"> <li>1. Never</li> <li>2. Sometimes</li> <li>3. Often</li> <li>4. Regularly</li> </ol>	No supervised exercise	Yes=response 1-2 No=response 3-4
	Do fun physical activities (like walking, swimming, rolling, wheelchair sports)	<ol style="list-style-type: none"> <li>1. Never</li> <li>2. Sometimes</li> <li>3. Often</li> <li>4. Regularly</li> </ol>	No fun physical activity	Yes=response 1-2 No=response 3-4
Dietary habits	On an average day, how many total hours do you watch TV, play video games, or use the computer?	<ol style="list-style-type: none"> <li>1. I do not watch television, play video games, or use the computer</li> <li>2. &lt;1h per day</li> <li>3. 1h per day</li> <li>4. 2h per day</li> <li>5. 3h per day</li> <li>6. 4h per day</li> <li>7. 5 or more hour per day</li> </ol>	Watch television ≥3h	Yes=response 5-7 No=response 1-4
	Include whole grains, raw fruits, and raw vegetables in my diet	<ol style="list-style-type: none"> <li>1. Never</li> <li>2. Sometimes</li> <li>3. Often</li> <li>4. Regularly</li> </ol>	Not eating grain/fruit/vegetables regularly	Yes=response 1-2 No=response 3-4
Substance abuse	Eat a lot of different healthy foods every day	<ol style="list-style-type: none"> <li>1. Never</li> <li>2. Sometimes</li> <li>3. Often</li> <li>4. Regularly</li> </ol>	Not eating healthy food regularly	Yes=response 1-2 No=response 3-4

## APPENDIX-A (CONTINUED)

Smoking	During the past 30d, on how many days did you smoke cigarettes?	1. 0d 2. 1 or 2d 3. 3–5d 4. 6–9d 5. 10–19d 6. 20–29d 7. All 30d	Current cigarettes smoker	Yes=response 2–7 No=response 1
Alcohol abuse	During the past 30d, on how many days did you have at least one drink of alcohol?	1. 0d 2. 1 or 2d 3. 3–5d 4. 6–9d 5. 10–19d 6. 20–29d 7. All 30d	Current alcohol drinker	Yes=response 2–7 No=response 1
Binge drinking	During the past 30d, on how many days did you have five or more drinks of alcohol in a row, that is, within a couple of hours?	1. 0 d 2. 1 or 2d 3. 3–5d 4. 6–9d 5. 10–19d 6. 20–29d 7. All 30d	Current binge drinker	Yes=response 2–7 No=response 1
Illicit drug	Have you ever used illegal drugs?	1. Yes 0. No	Ever use of illicit drug	Yes= response 1 No = response 0
Other analysis variable General health	How do you describe your health in general?	1. Excellent 2. Very good 3. Good 4. Fair 5. Poor	Poor/fair health	Yes= response 4–5 No= response 1–3
Self-reported overweight	How do you describe your weight?	1. Very underweight 2. Slightly underweight 3. About the right weight 4. Slightly overweight 5. Very overweight	Overweight	Yes=response 4–5 No=response 1–3

In the article by van der Slot et al.<sup>1</sup> the authors wish to point out that there was an error in Table III. The *p* value for Depressive symptoms (CES–D≥16) should read 0.008.

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