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## Chronic pain prevalence and associated factors in adolescents with and without physical disabilities

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### Abstract

**AIM**—Adolescents with physical disabilities may have co-occurring chronic pain, but the prevalence and specific associated factors are unknown. The aims of this study were to determine (1) the prevalence of chronic pain in adolescents with physical disabilities and (2) whether known correlates of chronic pain in the general population are also present in young people both with physical disability and with chronic pain relative to peers.

**METHOD**—We conducted a secondary analysis of cross-sectional nationally representative data from the National Longitudinal Study of Adolescent to Adult Health. Multivariate linear regression analysis was used to identify demographic and psychosocial factors associated with chronic pain.

**RESULTS**—A total of 989 (4.3%) adolescents reported physical disabilities. They had a significantly higher rate of pain (27.2%) compared with able-bodied peers (15.6%,  $\chi^2=86.3550$ ,  $p<0.001$ ). There was no significant interaction between physical disability status and chronic pain in relation to depressive symptoms, anxiety, or insomnia.

**INTERPRETATION**—Adolescents with physical disabilities experience chronic pain at a significantly higher rate than able-bodied peers, but the comorbidity of physical disability and chronic pain is not related to depression, anxiety, or insomnia. Evaluation of chronic pain and tailored pain interventions need to be developed for this population.

It is estimated that 5.8% of children and adolescents in the USA have physical disabilities.<sup>1</sup> As a subpopulation, they have been identified as a global health priority by UNICEF.<sup>2</sup> Disability can conceptually be defined as 'difficulty or dependency in carrying out activities essential to independent living'.<sup>3</sup> The physical characteristics of these disabilities may comprise difficulty with gross-motor skills such as walking; difficulty with fine-motor skills such as writing or eating; or altered muscle tone, paralysis, loss of, or inability to use, one or more limbs.

Limited available literature shows that children with physical disabilities are known to have worse physical and psychological health outcomes and poorer social support than able-bodied comparison groups.<sup>4</sup> A common symptom experienced by young people with physical disabilities is pain. Although chronic pain is well documented as having significant physical, psychological, and social impact among non-disabled young people, little research has been conducted to understand the prevalence and impact of chronic pain in young people with physical disabilities.<sup>5</sup> The limited evidence suggests that young people with physical disabilities may be at greater risk of having chronic pain<sup>6</sup>; and, given the nature of physical disabilities, these young people commonly report pain in more than one bodily site.<sup>7</sup> However, previous studies are limited by small sample sizes, and inclusion of only one specific physical disability (e.g. cerebral palsy<sup>8</sup> or neuromuscular disease),<sup>9</sup> make any conclusions about pain in this population very preliminary or disability-specific. This has hindered the development of interventions to manage pain in the broader population of adolescents with physical disabilities. Epidemiological research is necessary to better characterize the prevalence of pain and associated factors in adolescents with physical disabilities in order to guide future assessment and intervention efforts in this at-risk population.

In addition to general prevalence estimates, identifying the demographic and psychosocial factors that may be associated with chronic pain in this specific population of young people with physical disabilities is important for developing preventive interventions targeted to those at risk for co-occurring chronic pain. Such interventions are needed to help alleviate the impact of the co-occurrence of chronic pain and physical disabilities, decrease impaired functioning,<sup>6</sup> and reduce the economic, emotional, and social burden that is well known to this population during adulthood.

A range of demographic and psychosocial factors have been found to be associated with chronic pain in able-bodied populations in several pain conditions (e.g. musculoskeletal pain,<sup>10</sup> low back pain,<sup>11</sup> widespread pain,<sup>12</sup> and postsurgical pain).<sup>13</sup> Specifically, certain demographic characteristics (like female sex and older age)<sup>14</sup> and clinical factors (higher rates of insomnia,<sup>15</sup> increased levels of anxiety,<sup>16</sup> and more depressive symptoms)<sup>17</sup> have been found to be associated with pain and functional disability in young people.

Because young people with disabilities have unique characteristics and needs, it is unknown whether similar demographic and psychosocial factors would be associated with chronic pain in this population. For example, neurological impairments may disrupt sleep, muscular stiffness can be increased because of the disease or the use of a wheelchair, and depression

and anxiety symptoms may be increased owing to poorer social relationships and stigma. All of these factors may in turn influence the experience of chronic pain.

To characterize rates and correlates of chronic pain in young people with physical disabilities, we used cross-sectional data from the National Longitudinal Study of Adolescent to Adult Health (Add Health)<sup>18</sup> for secondary data analysis on a broad, population-level scale. This is the first nationally representative study to examine chronic pain in adolescents with physical disabilities. Our primary aim was to determine prevalence rates of chronic pain and its associated factors, including socio-demographic factors (age, sex, ethnic group, and income), perceived general health, and psychosocial factors (anxiety, depressive symptoms, insomnia) among adolescents with physical disabilities compared with adolescents without physical disabilities in the USA. Our secondary aim was to determine whether known correlates of chronic pain in the general population are also important correlates of chronic pain among adolescents with physical disabilities. Specifically, on the basis of available literature in pediatric chronic pain, we tentatively hypothesized that young people both with physical disabilities and with chronic pain would have significantly higher depressive symptoms, anxiety symptoms, and insomnia, compared with young people with physical disabilities without chronic pain or able-bodied young people.

## METHOD

### Procedures

We used data from the National Longitudinal Study of Adolescent to Adult Health (Add Health). Add Health is a nationally representative sample of adolescents, living and attending school in the USA.<sup>18</sup> Add Health uses a complex, multistage sample design to provide data that is nationally representative of the adolescent population in the USA. Further information on Add Health is publicly available online (<http://www.cpc.unc.edu/projects/addhealth>). Our current study uses data from Add Health's Wave I, which was collected through in-home interviews, from 1994 to 1995. Data collection and procedures were approved by the Institutional Review Board of the University of North Carolina. Written informed consent was obtained before the interviews. The present secondary analysis was also reviewed and approved by the Institutional Review Board at Seattle Children's Hospital.

Add Health is unique in gathering extensive information about participants' socio-demographic characteristics and health, including physical disabilities, chronic pain, insomnia, and mental health symptoms. Thus, Add Health provides a rich environment to study factors associated with physical disabilities in participants. So far, two studies on physical disabilities have been published using the Add Health database: Cheng and Udry<sup>19</sup> reported on sexual behaviors, while Queirós et al.<sup>20</sup> reported on socio-economic outcomes of adolescents with physical disabilities. However, no study on chronic pain among adolescents with physical disabilities in the Add Health database has yet been reported.

## Measures

**Sample characteristics and demographics**—We extracted parent-reported data on socio-demographic variables and other sample characteristics including sex, age, ethnic group (white, non-Hispanic, black, non-Hispanic, Hispanic, or other), parental income (US dollars), and physical aids used (i.e. braces, artificial limbs, canes, crutches or walkers, prescription shoes, and wheelchairs).

**Physical disabilities**—Adolescents with physical disabilities are identified in Add Health by four self-reported screening questions: (1) ‘do you have any difficulty using your hands, arms, legs, or feet because of a permanent physical condition?’; (2) ‘do you use a cane, crutches, walker, medically prescribed shoes, wheelchair, or scooter to get around because of a permanent physical condition?’; (3) ‘do you use a brace for your hand, arm, leg, or foot because of a permanent physical condition?’; and (4) ‘do you use an artificial hand, arm, leg, or foot?’. In total, 898 participants responded ‘yes’ to any of these questions and were identified as having a physical disability.

**Chronic pain**—Chronic pain was identified by asking participants to self-rate the frequency of each of the following types of pain occurring over the previous 12 months: (1) headache, (2) stomach ache, and (3) aches, pain, or soreness in muscles or joints. These are the most common types of chronic pain in children and adolescents. The response options included ‘never’, ‘just a few times’, ‘about once a week’, ‘almost every day’, ‘every day’, and ‘refused’. We classified chronic pain as pain occurring ‘almost every day’ or ‘every day.’ This conservative way of coding chronic pain has been used in previous studies with the Add Health sample.<sup>21</sup>

**Anxiety**—Anxiety symptoms were measured by asking participants whether they had each of the following physiological symptoms of anxiety in the previous year: (1) felt hot all over suddenly, for no reason, (2) cold sweats, (3) chest pains, (4) fearfulness, and (5) trouble relaxing. Responses to each symptom were measured on a 0 to 4 Likert scale ranging from ‘never’ to ‘every day.’ Scores were summed to provide a range of 0 to 20, with higher scores indicating higher levels of anxiety. This measure of anxiety has been used in previous studies with the Add Health sample.<sup>21</sup>

**Depressive symptoms**—Depressive symptoms were measured using the 20-item Center for Epidemiological Studies-Depression Scale<sup>22</sup> completed by participants. Responses to each of the 20 items were recorded on a Likert scale ranging from ‘never/rarely’ to ‘most/all of the time’ about symptoms experienced during the previous week. Likert scores were summed to provide a range of 0 to 60 with higher scores indicating more depressive symptoms.

**Insomnia**—Insomnia was assessed by asking participants whether they had trouble falling asleep or staying sleep. Those that reported ‘every day’ or ‘almost every day’ during the previous year were classified as having insomnia symptoms, similar to other studies.<sup>23</sup>

## Statistical analyses

Data analyses were conducted using the survey package contained in Stata version 12.1 (StataCorp College Station, TX, USA). As recommended, we used sampling weights, regional stratification, and primary sampling unit information to provide nationally representative estimates from the Add Health database. Consequently, descriptive statistics are presented as weighted percentages, means, and linearized standard errors. To address our primary aim, we first conducted bivariate analyses to compare rates of chronic pain between adolescents with and without physical disabilities using survey-adjusted Pearson  $\chi^2$  tests for categorical variables and Wald tests for continuous variables. To address the secondary aim, we conducted three linear regression analyses to test whether the presence of both a physical disability and chronic pain in young people was associated with significantly higher depressive symptoms, anxiety symptoms, and rates of insomnia after controlling for the effects of sex, age, ethnic group, and income.

## RESULTS

### Socio-demographic and clinical characteristics

**Age, sex, ethnic group, and income**—The total sample consisted of 18 924 adolescents (mean age 16y 0 mo) who were representative of the US adolescent population in 1995 to 1996, with 9288 (50.9%) identified as male and 9644 (64.9%) identified as white, non-Hispanic. The sample contained 898 participants with physical disabilities (4.3%). Participants with physical disabilities had socio-demographic characteristics similar to able-bodied adolescents (see Table I).

**Types of pain and assistive devices used**—Regarding the type of chronic pain, the most common locations were pain in muscles and joints (16.5%), headaches (12.2%), and stomach aches (6.4%). Concerning the assistive devices used by the participants with physical disabilities, we found that 28.5% used braces, 3.6% used prescription shoes, 3.4% used crutches or a walker, 3.1% used a wheelchair, 2% had an artificial limb, and 0.5% needed a cane. Use rates were similar between those with and without chronic pain for all the devices except for braces (chronic pain 36.0%, no chronic pain 25.7%;  $p=0.029$ ) and prescription shoes (chronic pain 6.6%, no chronic pain 2.5%;  $p=0.023$ ).

### Aim 1: prevalence of chronic pain

In unadjusted bivariate analysis, young people with physical disabilities had a significantly higher rate of chronic pain compared with able-bodied young people (27.2% versus 15.1%;  $\chi^2=86.355$ ,  $p<0.0001$ ). Furthermore, young people with physical disabilities also had higher rates of depressive symptoms (mean score 13.2 vs 11.6;  $F=11.8$ ,  $p=0.0008$ ), anxiety symptoms (mean score 2.9 vs 2.3;  $F=10.71$ ,  $p=0.001$ ), insomnia (14.5% vs 10.1%;  $\chi^2=16.48$ ,  $p=0.007$ ), and were more likely to rate their general health as poor (11.3% vs 6.8%;  $\chi^2=23.56$ ,  $p=0.001$ ) compared with able-bodied young people (see Table I).

### Aim 2: correlates associated with chronic pain and physical disabilities

In the regression analyses, we found main effects of having chronic pain on increased rates of depression, insomnia, and anxiety symptoms, controlling for demographics. However,

contrary to hypotheses, there was not a main effect for having a physical disability on depressive, insomnia, and anxiety symptoms, nor was there an interaction effect between physical disabilities and chronic pain. This suggests that young people with both problems did not report greater depression, anxiety, or insomnia relative to young people with physical disabilities without chronic pain or able-bodied young people.

## DISCUSSION

In the present study, we sought to describe the prevalence of chronic pain and its associated correlates in a nationally representative sample of adolescents with physical disabilities. Consistent with our primary hypothesis, the prevalence of chronic pain in adolescents with physical disabilities was almost double that of able-bodied adolescents (27.2% vs 15.1%). Rates of chronic pain found in able-bodied adolescents were consistent with estimates found broadly in the pediatric pain literature (11–38%)<sup>24</sup> and rates of chronic pain found in the sample with disabilities were also consistent with a study that found that 27% of a sample of young people with cerebral palsy ( $n=248$ ) had pain problems.<sup>8</sup> Furthermore, we also determined that adolescents with physical disabilities had higher rates of anxiety, depression, insomnia, and poorer general health compared with able-bodied adolescents (aim 1). These results provide both novel and important epidemiological data on these vulnerable young people, as previous studies were limited by small sample sizes.

Our secondary aim examined known correlates of chronic pain in the whole sample of adolescents with and without physical disabilities to detect whether young people with both physical disabilities and chronic pain were at risk for more psychosocial symptoms. After controlling for other demographic factors, having chronic pain was associated with higher symptoms of depression and anxiety and higher rates of insomnia. However, we failed to detect a main effect for having a physical disability or a significant interaction between chronic pain and physical disability. Thus, our hypothesis that young people with physical disabilities and chronic pain would be at risk for greater associated psychosocial symptoms was not supported. Further research is needed to understand why minorities differ from white participants and what is the role of economic income.

Taken together, the pattern of findings detected in this study provides preliminary evidence that chronic pain is a common consequence of having a physical disability. This lends support for future research on extending multidisciplinary, evidence-based pediatric pain interventions to young people with physical disabilities. However, although as a group young people with physical disabilities had higher rates of psychosocial symptoms than able-bodied young people, the co-occurrence of chronic pain did not place them at particular increased risk compared with young people with physical disabilities without co-occurring chronic pain. It will be important in future research to also assess other relevant areas not measured in this study such as fatigue, eating and drinking issues, neurocognitive impairment, and communication, which may also increase risk for psychosocial symptoms.

On the other hand, some findings of the association between insomnia and pain have been reported in a previous smaller study ( $n=505$ ), which found that pain was the strongest predictor for sleep problems in a sample of children and adolescents with physical

disabilities (e.g. cerebral palsy, spina bifida, muscular dystrophy), as reported by their parents.<sup>25</sup> A comprehensive assessment of sleep problems including both physiological sleep disorders (e.g. sleep-disordered breathing) and behavioral sleep disorders (e.g. insomnia) is warranted in young people with physical disabilities and chronic pain.

The present study has certain limitations that should be considered when interpreting the results. First, we used cross-sectional data, so no inferences on cause and effect relationships could be made. Second, some information that would have allowed us to make more precise conclusions was not available. For example, there was limited information about pain within this large data set, and it did not include assessments of pain intensity, the duration of pain, or pain extent (the number of bodily areas with pain reported on a body map). There was also limited information about the physical disability such as diagnoses, the adolescent's current treatments, or a functioning index. However, as a proxy for functioning, we do present the information we have available (e.g. knowledge that all the participants were able to attend school, and specific assistive devices used). Without these key data, it is impossible to determine the degree to which pain affects the daily life of young people with physical disabilities, which is critical for determining the extent of pain-specific treatment needed for the population of adolescents with physical disabilities. It also must be acknowledged that the sample is representative of the US population, but generalizability beyond that is unknown. Furthermore, the age of the data warrants comment, as Wave I data in Add Health were collected in 1994 to 1995. However, given the lack of research on pain in young people with physical disabilities, it is important to use available, if older, data sources. Finally, the conservative approach used to classify pain as chronic may have led to lower rates of chronic pain and missed associations between the variables. Future longitudinal research considering pain intensity and location in young people with physical disabilities and specific diagnoses is warranted.

These results suggest that young people with disabilities are at risk for chronic pain and that they may have different needs for pain assessment and management. Of greatest importance, findings show that adolescents with physical disabilities experience chronic pain at higher rates than the general adolescent population. Thus, chronic pain assessment should be a routine aspect of clinical care of adolescents with physical disabilities and referral to multidisciplinary pediatric pain clinics should be considered for pain management. Findings from this study also have implications for tailoring interventions towards young people with physical disabilities. It would be crucial to determine the most effective techniques to use. For example, a study with adolescents with spina bifida and neuromuscular disease ( $n=70$ ) found that psychological functioning (anxiety, depression, and positive affect) was related to social support from family members but not from friends.<sup>4</sup> Thus, the nuances of these conditions should be well-studied before assuming that the techniques (or treatment goals) that work well for other clinical populations are going to work in the same way for adolescents with physical disabilities.

In conclusion, chronic pain and its correlates are important problems for adolescents with physical disabilities, as they are at higher risk of having chronic pain than other young people. The unique characteristics of this population call for further studies of the specific risk factors and correlates of chronic pain in adolescents with physical disabilities, which in

turn could direct the development and testing of new treatments targeting their specific needs.

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## ABBREVIATIONS

**Add Health**

National Longitudinal Study of Adolescent to Adult Health

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**What this paper adds**

- Chronic pain and its correlates are important problems for adolescents with physical disabilities.
- These adolescents present with higher rates of chronic pain than other young people.
- Chronic pain is associated with increased levels of depressive symptoms, anxiety, and insomnia regardless of disability status.

**Table I**

Socio-demographic and clinical characteristics of the adolescents

	Full sample (n=18 924)	Physical disabilities (n=898)	No physical disabilities (n=18 026)	<i>p</i>
Estimated US population	22 213 733	958 609	21 255 124	
Weighted % (SEM)	–	4.3 (0.5)	95.7 (0.5)	
Mean age, y:mo (SEM)	16:0 (0:1)	16:5 (0:1)	16:0 (0:1)	0.005
Female sex, % (SEM)	49.1 (0.6)	48.8 (3.5)	49.1 (0.5)	0.930
Ethnic group, % (SEM)				0.320
White, non-Hispanic	64.9 (2.9)	64.7 (5.3)	64.9 (2.9)	
Black, non-Hispanic	15.5 (2.0)	11.2 (2.1)	15.7 (2.1)	
Hispanic	12.1 (1.7)	16.0 (5.2)	11.9 (1.7)	
Other	7.5 (0.8)	8.1 (1.3)	7.5 (0.8)	
Mean parental income, US\$ (SEM)	45 189 (1704)	44 647 (3300)	45 213 (1727)	0.860
Mean anxiety symptoms, (SEM)	2.3 (0)	2.9 (0.2)	2.3 (0)	0.001
Mean depressive symptoms (SEM)	11.6 (0.1)	13.2 (0.5)	11.6 (0.1)	0.0008
Insomnia, % (SEM)	10.3 (0.3)	14.5 (1.8)	10.1 (0.3)	0.007
Chronic pain, % (SEM)	15.6 (0.5)	27.2 (2.9)	15.1 (0.5)	<0.0001
Brace use	2.5 (0.2)	28.5 (3.6)	1.3 (0.1)	<0.0001
Artificial limb use	0.2 (0.1)	2.0 (0.7)	0.1 (0.0)	<0.0001

Source: National Longitudinal Study of Adolescent to Adult Health. SEM, linearized standard error of the mean.

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**Table II**  
Multivariate associations of pain and physical disability with depressive symptoms

Variable	Coefficient ( $\beta$ )	Standard error	t	P> t	95% CI
Pain	4.43	0.30	14.65	<0.001	3.83–5.03
Disability	0.77	0.50	1.55	0.123	-0.21 to 1.76
Age	0.46	0.05	9.10	<0.001	0.36–0.56
Sex	1.62	0.19	8.38	<0.001	1.24–2.01
Ethnic group					
Black	1.40	0.29	4.83	<0.001	0.83–1.98
Hispanic	1.90	0.35	5.43	<0.001	1.21–2.59
Other	1.65	0.41	4.00	<0.001	0.83–2.47
Income	-0.013	0.002	-5.95	<0.001	-0.02 to -0.01
Constant	2.68	0.80	3.37	0.001	1.10–4.25

The reference category for sex is female and for ethnic group is white. No interaction effects between having chronic pain and a physical disability were found.

**Table III**  
Multivariate associations of pain and physical disability with insomnia symptoms

Variable	Coefficient ( $\beta$ )	Standard error	t	P> t	95% CI]
Pain	0.16	0.02	10.75	<0.001	0.13–0.19
Disability	0.01	0.02	0.66	0.510	–0.02 to 0.04
Age	<–0.01	<0.01	–0.66	0.511	–0.00 to 0.00
Sex	0.01	0.01	1.14	0.257	–0.01 to 0.02
Ethnic group					
Black	–0.01	0.01	–1.50	0.137	–0.03 to 0.00
Hispanic	<–0.01	0.01	–0.38	0.704	–0.02 to 0.02
Other	–0.01	0.01	–0.80	0.424	–0.04 to 0.02
Income	<–0.01	<0.01	–4.07	<0.001	–0.00 to –0.00
Constant	0.10	0.03	3.44	0.001	0.04–0.16

The reference category for sex is female and for ethnic group is white. No interaction effects between having chronic pain and a physical disability were found.

**Table IV**

Multivariate associations of pain and physical disability with anxiety symptoms

Variable	Coefficient ( $\beta$ )	Standard error	t	P> t	95% CI]
Pain	1.59	0.09	17.45	<0.001	1.41-1.77
Disability	0.12	0.12	0.94	0.348	-0.13 to 0.36
Age	-0.01	0.02	-0.82	0.412	-0.04 to 0.02
Sex	0.39	0.05	7.61	<0.001	0.29-0.49
Ethnic group					
Black	-0.08	0.08	-1.01	0.313	-0.24 to 0.08
Hispanic	0.04	0.08	0.56	0.577	-0.11 to 0.20
Other	0.25	0.09	2.84	0.005	0.08-0.43
Income	<-0.01	<0.01	-2.56	0.012	-0.00 to -0.00
Constant	2.05	0.25	8.32	<0.001	1.56-2.54

The reference category for sex is female and for ethnic group is white. No interaction effects between having chronic pain and a physical disability were found.