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ORIGINAL ARTICLE

Patient and caregiver knowledge of autonomic dysreflexia among youth with spinal cord injury

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Objectives: To describe the prevalence and knowledge of autonomic dysreflexia (AD) from patient and caregiver perspectives, and its relationship to the American Spinal Injury Association (ASIA) Impairment Scale (AIS) classification, level of injury, severity of injury, injury etiology, gender and race.
Methods: Participants were between 1 and 21 years old. Demographic information was collected from the medical records, and patients and caregivers were interviewed with the following questions: (1) Does the patient experience AD? (2) Does the patient/caregiver know what AD is? (3) Can the patient/caregiver name three signs/symptoms of an AD episode? (4) Does the patient/caregiver know how to treat AD?
Results: Overall, 40% of patients and 44% of caregivers said that the patient was symptomatic for AD. AD was more common in those with traumatic etiologies, in patients with injuries at or above T6 and those with greater injury severity as measured by the AIS. For patients and caregivers, AD was less common in the youngest age group (0–5 years old). Patients with greater knowledge of AD were more likely to have traumatic etiologies, have T6 or higher injuries, be in the oldest age at injury group, be older at time of examination and have had a shorter duration of injury.
Conclusions: AD seems to be more common in patients with traumatic injuries, older ages at injury, greater injury severity on the AIS and level of injury at or above T6.
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Keywords: spinal cord injury; autonomic dysreflexia; secondary medical complications

Introduction

Autonomic dysreflexia (AD) is a serious complication of spinal cord injury (SCI) that is typically seen in patients with injury levels at or above T6 and particularly in complete injuries.[1,2] Triggering factors for AD include distension of hollow organs, sexual activity, diseases of gastrointestinal tract, painful stimuli, skeletal fractures, hip dislocations and pregnancy.[3] The associated symptoms of AD include headache, flushing, sweating, nasal congestion, bradycardia, cardiac arrhythmia and anxiety.[3–5] The defining symptom of AD, however, is hypertension. Additionally, it should be noted that AD can take on a silent form, in which significant increases in blood pressure can occur without visible symptoms of AD.[6] When it is appropriately diagnosed, AD can be treated successfully; however, failure to do so can result in serious consequences, including death.[7] Occasionally, patients may be discharged from the hospital before the onset of AD and therefore education on the topic is critical.[8]

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Published rates of AD vary depending on the sample population. The National Spinal Cord Injury Statistical Center reported that 17% of patients in their database experienced AD, although this could not be confirmed retrospectively.[8] Subgroup differences related to severity of injury, age at injury, injury etiology and level of injury have also emerged in the existing literature on AD. In levels of injury at or above T6, prevalence ranges from 48 to 83%. Vogel *et al.*[9] reported an AD prevalence of 54% among adults with pediatric onset SCI with C1-T6 injuries. Helkowski *et al.*[8] reported that 10% of their patients with motor complete SCI experienced AD during their initial hospital stay. McKinley *et al.*[5,10] reported a greater incidence of AD in traumatic injuries versus non-traumatic injuries and that AD was one of the most common long-term secondary medical complications of SCI. Hickey *et al.*[11] reported that AD was more common in children injured between 6 and 13 years of age compared with those who were injured younger than 6 years and was more common in complete lesions.

Patient and caregiver education about SCI and related secondary medical complications, such as AD, is an essential component to a successful transition to home and community.[12,13] Additionally, proper education, and

knowledge about SCI and associated complications will help patients and caregivers direct their care throughout their lifespan.

Purpose
This study is a part of a larger multicenter research effort aimed at establishing the utility of the International Standards for Neurological Classification of Spinal Cord Injury (ISCSCI) in children and youth. The primary goal of this study is to describe the incidence of knowledge of AD from patient and caregiver perspectives, and examine the incidence on the basis of American Spinal Injury Association (ASIA) Impairment Scale (AIS) classification, level of injury, severity of injury, injury etiology, gender and race.

Materials and methods

Participants
A total of 215 participants were enrolled in this multicenter research effort. Participants were between the ages of 1 and 21 years with a stable injury as evidenced by no neurological change within the past 3 months. Participants had to have been receiving care at either Shriners Hospitals for Children in Chicago or Philadelphia. All participants who met the above criteria and who presented to the hospital for admission were approached about the study.

Procedure
The study protocol, consent, assent and HIPPA forms were all reviewed and approved by the Institutional Review Board at each participating center. Informed consent was obtained from all participants and their caregivers as appropriate, and the ethical treatment of human participants was followed throughout the research process.

Instruments
Demographic information was collected from the medical records for all participants, including gender, ethnicity, date of birth, date of injury, age at injury and injury etiology. Level of injury, severity of injury and AIS classification were determined by formal motor, sensory and anorectal examinations on the basis of the 2002 ISCSCI. Additionally, patients and families were asked four questions about AD. Those questions were: (1) Does the patient experience AD? (2) Does the patient/caregiver know what AD is? (3) Can the patient/caregiver name three signs/symptoms of an AD episode? (4) Does the patient/caregiver know how to treat AD? These were all yes/no questions, and patients and caregivers were allowed to expand on questions (1) and (2) with comments. To get a 'yes' for questions (3) and (4), patients and caregivers had to be able to name three signs/symptoms of an AD episode and be able to give us a medically appropriate example of how they would treat it.

Analysis
The Statistical Package for the Social Sciences (SPSS, version 15.0) was used to analyze the data. Descriptive statistics were used to describe knowledge of AD among patients and caregivers, and χ^2-analyses were used to examine differences among subgroups, including severity of injury, age at injury, injury etiology and level of injury. Independent samples *t*-test was used to compare means. Multiple logistic regression analyses were performed with the independent variables being gender, race, etiology of injury, age at injury, level of injury and ASIA classification.

Results

The demographics of the study sample are presented in Table 1. 59% of participants were male, 76% were Caucasian, 54% had tetraplegia, 78% had injuries at or above T6 and 51% had complete lesions. 48% of youth were injured due to vehicular accidents and their mean age at injury was 9.1 years.

Does the patient experience AD according to the patient/caregiver?
Overall, 40% of patients and 44% of caregivers said that the patient did experience or was symptomatic for AD. When looking solely at those with injury levels at or above T6, 50% of patients and 53% of caregivers of those patients said that they did experience AD. The incidence of AD, as a function of gender, race, injury etiology, age at injury, level of injury and AIS classification, is examined first according to patient responses and second for caregiver responses (Table 2).

There were no significant associations between incidence of AD and gender, race or duration of injury for the patient

Table 1 Participant demographics

Characteristic	*% of participants* (n = *215*)
Sex	
Male	59%
Female	41%
Race	
Caucasian	76%
Hispanic	11%
African-American	8%
Asian	2%
Type of injury	
Tetraplegia	54%
Paraplegia	46%
Severity of injury	
Complete	51%
Incomplete	49%
Level of injury	
T6 and above	78%
Below T6	22%
Cause of injury	
Vehicular	48%
Medical/surgical	23%
Sports	14%
Violence	9%
Falls/flying objects	6%
Watercrafts	1%
Mean age at injury	9.1 years

Table 2 The relationship between autonomic dysreflexia and demographic and injury-related factors

Characteristic	*History of AD per patient*	P-*value*	*History of AD per caregiver*	P-*value*
All subjects	40%		44%	
Gender		$\chi^2=0.769$, $P=0.381$		$\chi^2=1.07$, $P=0.301$
Male	43%		48%	
Female	37%		39%	
Race		$\chi^2=1.57$, $P=0.814$		$\chi^2=3.29$, $P=0.511$
Asian	67%		0%	
Black	40%		27%	
Hispanic	32%		40%	
Caucasian	41%		47%	
Etiology		$\chi^2=4.91$, $P=0.027$		$\chi^2=4.37$, $P=0.037$
Traumatic	44%		50%	
Non-traumatic	24%		30%	
Age at injury (years)		$\chi^2=18.64$, $P<0.001$		$\chi^2=7.34$, $P=0.025$
0–5	19%		35%	
6–13	45%		42%	
14–21	56%		64%	
Level of injury		$\chi^2=13.53$, $P<0.001$		$\chi^2=9.53$, $P=0.002$
T6 and above	48%		53%	
Below T6	12%		17%	
ASIA classification		$\chi^2=10.76$, $P=0.013$		$\chi^2=9.35$, $P=0.025$
A	40%		54%	
B	54%		59%	
C	43%		33%	
D	11%		15%	
Mean age at follow-up (years)				
Experience AD	16.0	$P<0.001$	12.9	$P=0.003$
Do not experience AD	13.4		10.6	
Duration of injury (years)				
Experience AD	4.3	$P=0.066$	4.6	$P=0.809$
Do not experience AD	5.5		4.8	

Abbreviation: ASIA, American Spinal Injury Association.

responses. Significant differences were found for the remaining variables. AD was significantly more common in traumatic etiologies, injuries at or above T6 or those with greater injury severity, as measured by the AIS. AD was significantly less common in the youngest age group (0–5 years old) compared with the two older age groups (6–13 and 14–21 years). Patients who experienced AD were significantly older at the time of questionnaire compared with patients who did not experience AD. Using multiple logistic regression analysis, this question was significantly associated with level of injury and age at injury. Children with injury levels at or above T6 and those in the oldest age at injury group were more likely to say that they experienced AD (Table 3).

In caregiver responses, there were no significant associations in AD prevalence for gender, race or duration of injury. Significant differences were found for the remaining variables (Table 2). Using multiple logistic regression analysis, there was an association with level of injury and AIS classification. Caregivers of people with injury levels at or above T6 and those with a greater injury severity, as measured by the AIS, were more likely to experience AD (Table 3).

Does the patient/caregiver know what AD is?
Examining patient responses for this question, no significant associations were found for gender, race or AIS classification. Patients who were able to define AD were more likely to have traumatic etiologies, have T6 or higher injuries, have a shorter duration of injury and be in the oldest age at injury group (Table 4).

Significant associations between variables and knowledge regarding definition of AD were the same for the caregiver and the patient groups except that duration of injury was not significant in the caregiver group.

Can the patient/caregiver identify three signs/symptoms associated with an AD episode?
Examining patient's ability to identify three signs/symptoms of AD found no associations for gender, race or AIS classification. Patients with the ability to name three signs/symptoms of AD, however, were more likely to have traumatic injuries, have T6 or higher injuries, have a shorter duration of injury and be in the oldest age at injury group. For caregiver responses to the same question, the significant relationships were found only for level of injury and age of child at the time of examination (Table 5).

Does the patient/caregiver know how to appropriately treat an AD episode?
When asked whether they knew how to treat AD, there were no significant associations found for gender, race or AIS classification for the patient responses. Patients who were able to express how to treat AD were more likely to have traumatic etiologies, have an injury level at or above T6, have a shorter duration of injury and be in the oldest age at injury group. The only significant associations in the caregiver responses to this question were for etiology, level of injury, age at injury and age of patient at time of examination. Unlike the patient group, there was no significant association found with duration of injury (Table 6).

Of the patients with a positive history of experiencing AD, 15% did not know the definition of AD, 20% could not identify three signs/symptoms of AD and 6% said they did not know how to treat an AD episode if it were to occur. For the caregivers of patients who experienced AD, 9% did not know the definition of AD, 20% could not identify three signs/symptoms and 9% said they did not know how to treat an AD episode (see Table 7).

Table 3 Multiple logistic regression for experiencing autonomic dysreflexia

	Coefficient		*Nagelkerke* R^2	*Significance*
	β	*Standard error*		
Experiencing autonomic dysreflexia (patient)				
Level of injury (T6 and above vs below T6)	1.907	0.576	0.215	$P=0.001$
Age at injury (0–5, 6–13, 14–21)	−0.771	0.201	0.115	$P=0.000$
Experiencing autonomic dysreflexia (caregiver)				
Level of injury (T6 and above vs below T6)	1.692	0.598	0.103	$P=0.005$
ASIA classification	0.475	0.194	0.167	$P=0.014$

Abbreviation: ASIA, American Spinal Injury Association.

Table 4 The relationship between knowledge of autonomic dysreflexia definition and demographics and injury-related factors

Characteristics	*Patients who know definition*	P-*value*	*Caregivers who know definition*	P-*value*
All subjects	44%		53%	
Gender		$\chi^2=0.037$, $P=0.847$		$\chi^2=0.017$, $P=0.896$
Male	45%		52%	
Female	43%		54%	
Race		$\chi^2=4.40$, $P=0.355$		$\chi^2=4.93$, $P=0.295$
Asian	67%		0%	
Black	40%		46%	
Hispanic	26%		36%	
Caucasian	47%		57%	
Etiology		$\chi^2=15.76$, $P<0.001$		$\chi^2=7.24$, $P=0.007$
Traumatic	51%		60%	
Non-traumatic	14%		35%	
Age at injury (years)		$\chi^2=43.89$, $P<0.001$		$\chi^2=9.15$, $P=0.010$
0–5	15%		42%	
6–13	42%		54%	
14–21	71%		74%	
Level of injury		$\chi^2=7.39$, $P=0.007$		$\chi^2=10.09$, $P=0.001$
T6 and above	50%		61%	
Below T6	24%		25%	
ASIA classification		$\chi^2=1.35$, $P=0.717$		$\chi^2=4.99$, $P=0.172$
A	42%		59%	
B	52%		65%	
C	41%		39%	
D	45%		39%	
Mean age at follow-up (years)				
Know definition	16.5	$P<0.001$		$P=0.002$
Don't know definition	12.8		10.3	
Duration of injury (years)				
Know definition	3.6	$P<0.001$	4.3	$P=0.358$
Don't know definition	6.1		4.9	

Abbreviation: ASIA, American Spinal Injury Association.

Discussion

This study represents the largest cross-sectional study describing the prevalence of AD in children and youth with SCI and their caregivers. The 50% of patients and 53% of caregivers in the T6 and higher population, who said they did experience AD, are comparable with earlier studies of pediatric onset and adult onset SCI. Another study of pediatric onset SCI found an AD prevalence of 51% in the T6 and higher population[11] and a study of medical complications in a population of adults with pediatric onset SCI found the prevalence of AD to be 54%.[9]

For the purpose of this discussion, the patient responses to the questions were reviewed, as the caregiver results were similar. Comparable with McKinley *et al.*'s[5,10] findings, we found a higher prevalence of AD with traumatic injuries (44%) versus non-traumatic injuries (24%). Additionally, our findings of a higher prevalence of AD in the 6–13 age at injury group (45%) versus the 0–5 age at injury group (19%) replicated the findings in another study by Hickey *et al.*[11] Further stratification by age found that injured between 14 and 21 years of age had the highest prevalence of AD (56%).

As our findings show that more patients with traumatic injuries experience AD, it should not be surprising that more patients with traumatic injuries were able to identify three signs/symptoms of AD, more likely to be able to define AD and were more likely to know how to treat an AD episode versus the non-traumatic group. Additionally, as would be expected, as the age of the patient increased, the patient was more likely to be able to identify three signs/symptoms of an AD episode, more likely to be able to define AD and more likely to know how to treat AD. This may be due to one of two things: Older kids may just be more knowledgeable about their injury and secondary complications and therefore better able to verbalize responses to these questions, or as was shown with our study population, it may be because older kids are more likely to experience AD in the first place. Although not a significant finding, in our study population, the mean age of patients with T6 and above injuries was slightly higher than those with injuries at or below T6, again pointing to the possibility that older kids are more likely to have injury levels at or above T6 and therefore more likely to experience AD.

Table 5 The relationship between knowledge of autonomic dysreflexia symptoms and demographic and injury-related factors

Characteristic	*Patients who know three symptoms*	P-*value*	*Caregivers who know three symptoms*	P-*value*
All subjects	35%		41%	
Gender		$\chi^2=0.033$, $P=0.855$		$\chi^2=0.065$, $P=0.798$
Male	36%		42%	
Female	34%		39%	
Race		$\chi^2=8.91$, $P=0.063$		$\chi^2=5.29$, $P=0.259$
Asian	67%		0%	
Black	20%		27%	
Hispanic	13%		21%	
Caucasian	39%		45%	
Etiology		$\chi^2=6.05$, $P=0.014$		$\chi^2=2.17$, $P=0.141$
Traumatic	39%		44%	
Non-traumatic	17%		31%	
Age at injury (years)		$\chi^2=35.02$, $P<0.001$		$\chi^2=4.50$, $P=0.105$
0–5	15%		34%	
6–13	23%		38%	
14–21	60%		56%	
Level of injury		$\chi^2=7.61$, $P=0.006$		$\chi^2=11.12$, $P=0.001$
T6 and above	41%		50%	
Below T6	15%		13%	
ASIA classification		$\chi^2=4.59$, $P=0.205$		$\chi^2=5.92$, $P=0.116$
A	28%		41%	
B	46%		63%	
C	39%		33%	
D	40%		31%	
Mean age at follow-up (years)				
Know signs and symptoms	17.0	$P<0.001$	13.1	$P=0.005$
Don't know signs and symptoms	13.1		10.7	
Duration of injury (years)				
Know signs and symptoms	4.0	$P=0.030$	4.6	
Don't know signs and symptoms	5.5		4.7	$P=0.005$

Abbreviation: ASIA, American Spinal Injury Association.

Table 6 The relationship between knowledge of how to treat autonomic dysreflexia and injury-related factors

Characteristic	*Patient knows how to treat AD*	P-*value*	*Caregiver knows how to treat AD*	P-*value*
All subjects	43%		47%	
Gender		$\chi^2=1.48$, $P=0.224$		$\chi^2=0.186$, $P=0.667$
Male	47%		49%	
Female	37%		45%	
Race		$\chi^2=1.92$, $P=0.750$		$\chi^2=9.03$, $P=0.060$
Asian	50%		0%	
Black	46%		11%	
Hispanic	28%		31%	
Caucasian	45%		55%	
Etiology		$\chi^2=10.45$, $P=0.001$		$\chi^2=5.47$, $P=0.020$
Traumatic	50%		54%	
Non-traumatic	17%		30%	
Age at injury (years)		$\chi^2=24.74$, $P<0.001$		$\chi^2=6.91$, $P=0.032$
0–5	18%		38%	
6–13	43%		46%	
14–21	66%		68%	
Level of injury		$\chi^2=8.59$, $P=0.003$		$\chi^2=15.19$, $P<0.001$
T6 and above	49%		58%	
Below T6	14%		6%	
ASIA classification		$\chi^2=595$, $P=0.114$		$\chi^2=5.54$, $P=0.136$
A	40%		52%	
B	58%		65%	
C	39%		27%	
D	25%		46%	
Mean age at follow-up (years)				
Knows how to treat AD	16.2	$P<0.001$	13.0	$P=0.008$
Does not know how to treat AD	13.1		10.6	
Duration of injury (years)				
Knows how to treat AD	4.0	$P=0.003$	4.7	$P=0.663$
Does not know how to treat AD	6.3		5.0	

Abbreviation: ASIA, American Spinal Injury Association.

For the patient group, significant findings resulted for all four questions for duration of injury meaning that the less the duration of the injury, more likely the patient was to experience AD, define AD, identify three signs/symptoms of AD and know how to treat an AD episode. Interestingly, duration of injury was not associated with any of the four questions in the caregiver group.

Etiology, age at injury, level of injury, age at follow-up and duration of injury were all significantly associated with all four questions. ASIA classification, however, was only significantly associated with whether or not the patient experiences AD, but was significant in both the patient and the caregiver group, and was significant in the regression analysis for the caregiver group.

Although there was increased incidence of AD in patients whose levels of injury were at or above T6 (48%), four (12%) patients with injuries at T8, T10, T11 and T12 reported experiencing AD. Causes for AD in these patients included waiting too long to catheterize (in two of the patients) during therapy, and a blocked indwelling catheter. Overall, only 24% of patients with injury levels below T6 were able to define AD, only 15% were able to name three signs/symptoms of AD and only 14% knew how to treat an AD episode.

Table 7 The relationship between experiencing AD and knowledge of AD

Knowledge	*Positive history of AD per patient*	*Positive history of AD per caregiver*
Did not know definition of AD	15% ($n=15$)	9% ($n=6$)
Could not ID 3 signs/symptoms of AD	20% ($n=24$)	20% ($n=16$)
Did not know how to treat an AD episode	6% ($n=5$)	9% ($n=5$)

Abbreviations: AD, autonomic dysreflexia; ID, identify.

As seen in Table 7, of the 40% of patients and 44% of caregivers who claimed that they or the patient was symptomatic for AD, there were a surprising amount who did not know the definition of AD or did not recognize the term AD when first asked, could not identify three signs/symptoms of an AD episode and were unable to state how they would treat an AD episode if it were to occur (see Table 7).

As clinicians responsible for educating patients and caregivers of patients with SCIs, it is vital that not only those patients at highest risk for AD receive immediate and ongoing education about AD, but that all patients and caregivers of patients with SCIs, regardless of level of injury must be properly educated about AD, its associated risks, signs and symptoms of an AD episode, and how to properly treat AD if it occurs. Considerable education regarding SCI and its secondary complications will assist the patient and caregivers with a successful transition to home and community, and will help the patient in directing his or her ongoing care throughout their lifespan. Finally, as we tend to see an increase in the incidence of AD in the adolescent group, perhaps patients who are injured as young children need to be re-educated about AD as they approach adolescence.

The findings and implications of this study are limited due to the fact that answers to the four questions are only as per patient and caregiver report. When possible, patients were interviewed separately from caregivers; however, due to circumstances, many patients and caregivers were interviewed about symptoms of AD and knowledge of AD at the same time and therefore may have been more likely to give the same answer. Additionally, the interview questions were aimed at symptomatic AD and cannot account for instances of silent or asymptomatic AD.

Conclusion

AD as a secondary complication seems to be more common in patients with traumatic injuries, older ages at injury, greater injury severity and whose levels of injury are at or above T6.

Additional prospective studies, which include medical chart reviews and evidence of AD as diagnosed by a physician, as well as the time frame for the typical first appearance of AD in the pediatric SCI population, would help to more clearly outline the importance of AD education in the spinal cord population.

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