

**Children with ACC and Their Siblings:
How Alike Are They?**

Gary L. Schilmoeller, Ph.D.

Kathryn J. Schilmoeller, Ph.D.

Shihfen Tu, Ph.D.

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General information about the survey:

- A survey of 189 individuals with ACC and their siblings (total of 378 individuals) was conducted in fall 2002 and spring 2003.
- The survey was based on information presented in studies of people with ACC by O'Brien (1994) and Schilmoeller & Schilmoeller (2000) as well as from reports of parents and individuals with ACC who shared information with The ACC Network and on the ACC-L listserv for topics pertaining to ACC.
- This information represents participants who were reported to have complete (143) or partial (46) ACC, regardless of whether or not they had any other reported concurrent conditions (e.g., seizures, autism, mental retardation, etc). The results must be interpreted cautiously. Differences between children with ACC and their siblings might be due to ACC or due to some combination of the ACC and other concurrent conditions or due to the other concurrent conditions but not the ACC.
- We selected a subset of participants with Primary ACC - that is, these individuals had few or no other reported concurrent conditions - to attempt to clarify what might be due specifically to ACC. There were only 27 of these participants, 18 with complete ACC and 9 with partial ACC. We compared them with their siblings to see what results still might be different between these two groups. Differences between these two groups more likely are due to ACC rather than other conditions (e.g., seizures, mental retardation, etc.). However, the differences still could be due to some other variable that the two groups share in common.
- These results are preliminary and more detailed study is needed to determine or confirm which differences are due specifically to ACC.

Characteristics of the Sample at the time of the survey

- | | |
|---|-------------|
| • Mean age of individuals with ACC | 8.1 years |
| • Mean age of siblings | 11.9 years |
| • Mean age of mothers | 40.42 years |
| • Mean age of fathers | 42.96 years |
| • Mean educational level of respondent | 14.77 years |
| • Mean educational level of spouses
of respondents | 14.95 years |

Table 1: Comparison of Mean Age When Individuals with ACC and Siblings Met Developmental Milestones

Milestone	Mean Age in Months When Milestone Was Met*				
	Siblings	Child/ACC	50%*	75%*	90%*
Lift Head	5.44	4.99			
<u>Roll Over**</u>	<u>3.61</u>	<u>7.76</u>			
<u>Sit alone***</u>	<u>5.81</u>	<u>11.87</u>	5.5 mo	6.5 mo	7.8 mo
<u>Stand (hold on)</u>	<u>8.20</u>	<u>16.40</u>	7.6 mo	9.5 mo	10.0 mo
<u>Crawled</u>	<u>7.64</u>	<u>14.66</u>			
<u>Stand Alone</u>	<u>10.01</u>	<u>19.40</u>			
<u>Walk Alone</u>	<u>11.59</u>	<u>22.98</u>	12.1 mo	13.5 mo	14.3 mo
Walk up stairs	16.27	29.74			
Talked – one word	14.96	24.69	12.8 mo	15.0 mo	20.5 mo
<u>Toilet trained</u>	<u>29.85</u>	<u>48.15</u>			
<u>Ride a bike</u>	<u>60.19</u>	<u>76.07</u>			

Frankenburg, W.K., Dodds, J.B., & Fandal, A.W. (1970). Denver Developmental Screening Test. Denver Co: University of Colorado Medical Center.

*Age when given percentage of normative sample met this developmental milestone.

****Milestones in bold** indicate that individuals with ACC met milestone significantly later than siblings when looking at all of the 189 matched pairs where both the individual with ACC and the sibling had met the milestone.

*****Milestones in bold and underlined** indicate that individuals with Primary ACC met milestone significantly later than siblings when looking at all of the 27 matched pairs where both the individual with ACC and the sibling had met the milestone.

Comparison of eating and elimination characteristics (See Table 2)

- **Inadequate sucking reflex at birth:** About 40 in 100 children with ACC (40.6%) had an inadequate sucking reflex compared with only about 20 in 100 (19.0%) of their siblings.
- **Gastric feeding tube:** About 20 in 100 (19.5%) children with ACC had a gastric feeding tube at some time compared with 1 in 100 (1.1%) of their siblings.
- **Swallowing difficulty:** About 38 in 100 (37.6%) children with ACC experienced swallowing difficulty at some time compared with about 3 in 100 of the siblings (2.9%).
- **Chewing difficulty:** About 52 in 100 (51.9%) children with ACC experienced chewing difficulty at some time compared with about 1 in 100 (0.6%) of the siblings.
- **Difficulty with bladder control:** Slightly more than 60 in 100 (60.3%) children with ACC experienced difficulty with bladder control at some time compared with only about 10 in 100 (11.8%) of the siblings.
- **Difficulty with constipation:** A little more than 55 in 100 (55.6%) children with ACC experienced difficulty with constipation at some time compared with only about 20 in 100 (20.2%) of their siblings.

Table 2: Comparison of Eating and Elimination Characteristics for Individuals with ACC and Their Siblings (N = 189 pairs)

Physical Characteristic	
Inadequate sucking reflex at birth	*ACC > Siblings
Gastric feeding tube	*ACC > Siblings
Swallowing difficulty	*ACC > Siblings
Chewing difficulty	*ACC > Siblings
Difficulty with bladder control	*ACC > Siblings
Difficulty with constipation	*ACC > Siblings

*ACC > Siblings = More Individuals with ACC were reported to have these characteristics than their siblings

Comparison of sensation and motor skills (See Table 3)

- **Pain tolerance:** About 56 of 100 (56.2%) children with ACC showed little or no pain perception or less pain perception than average compared with only about 4 in 100 (4.4%) siblings. Comparison of sibling pairs show that the children with ACC have a significantly higher tolerance for pain than their siblings.
 - This significant difference does **NOT** exist when we compared the children with Primary ACC and their siblings.

- **Sensitivity to touch:** Respondents reported that many more children with ACC (about 47 in 100 or 46.7%) showed more or much more sensitivity to being touched by others than did their siblings (about 6 in 100 or 6.5%). Comparison of sibling pairs show that the children with ACC have a significantly higher sensitivity to touch than their siblings.
 - This significant difference does **NOT** exist when we compared the children with Primary ACC and their siblings.

- **Motor skills:** Parents reported that children with ACC were less skilled at general motor tasks (e.g., throwing and catching a ball, running, hopping and jumping) than their siblings. Comparison of sibling pairs show that the children with ACC have a significantly lower mean score for motor skill tasks than their siblings.
 - These mean scores also were significantly lower for the children with Primary ACC and their siblings.

- **Self-help skills:** Children with ACC had more difficulty handling self-help skills (e.g., buttoning clothes, zipping, brushing own teeth) than siblings. Comparison of sibling pairs show that the children with ACC have a significantly lower mean score for motor skill tasks than their siblings.
 - These mean scores also were significantly lower for the children with Primary ACC than for their siblings.

Table 3: Comparison of Sensation and of Motor Skills for Individuals with ACC and Their Siblings

	All individuals with ACC & Their Siblings (N = 189 pairs)	Individuals with Primary ACC & Their Siblings (N = 27 pairs)
High tolerance for pain	*ACC > Siblings	No difference
Sensitivity to touch	*ACC > Siblings	No difference
Motor skills	**ACC < Siblings	**ACC < Siblings
Self-help skills	**ACC < Siblings	**ACC < Siblings

*ACC > Siblings = Individuals with ACC had scores significantly higher than their siblings

**ACC < Siblings = Individuals with ACC had scores significantly lower than their siblings

Comparison of social behavior (See Table 4)

- **Social Interaction:** Parents reported that their children with ACC were slightly less capable in their social interactions with peers, strangers, and family members than were the siblings. Comparison of sibling pairs show that the children with ACC have a significantly lower mean score for social interaction skills than their siblings.
 - These mean scores were **NOT** significantly different when we compared the children with Primary ACC and their siblings.
- The children with ACC experienced more **social difficulties** (e.g., dominating conversations, unusual facial expressions) than their siblings. Comparison of sibling pairs show that the children with ACC have a significantly higher score for social difficulty than their siblings.
 - These mean scores also were significantly higher for the children with Primary ACC than for their siblings.
- Children with ACC were reported to be more likely to **show autistic-like** behaviors than their siblings. Comparison of sibling pairs show that the children with ACC have a significantly higher mean score for autistic-like behavior than their siblings.
 - These mean scores also were significantly higher for the children with Primary ACC than for their siblings even though the children with Primary ACC did NOT have a diagnosis of autism.
- Children with ACC were reported to be **less happy** or slightly **moodier** than their siblings. Comparison of sibling pairs show that the children with ACC have a significantly lower mean score for positive mood affect than their siblings.
 - These mean scores were **NOT** significantly different when we compared the children with Primary ACC and their siblings.
- Children with ACC were reported to be slightly more **aggressive** than their siblings. Comparison of sibling pairs show that the children with ACC have a significantly higher mean score for aggressive behavior than their siblings.
 - These mean scores also were significantly higher for the children with Primary ACC than for their siblings.

Table 4: Comparison of Social Behavior for Individuals with ACC and Their Siblings

	All individuals with ACC & Their Siblings (N = 189 pairs)	Individuals with Primary ACC & Their Siblings (N = 27 pairs)
General social interaction	**ACC < Siblings	No difference
Social difficulty	*ACC > Siblings	*ACC > Siblings
Show autistic-like behaviors	*ACC > Siblings	*ACC > Siblings
Positive mood behavior	**ACC < Siblings	No difference
Aggressive behavior	**ACC > Siblings	No difference

*ACC > Siblings = Individuals with ACC had scores significantly higher than their siblings

**ACC < Siblings = Individuals with ACC had scores significantly lower than their siblings

Comparison of learning (cognitive) characteristics (See Table 5)

- **Abstract reasoning:** About 74 of 100 (73.9%) children with ACC often or almost always had difficulty with abstract reasoning compared with only 13% of the siblings. Comparison of sibling pairs show that the children with ACC have a significantly higher mean score for difficulty with abstract reasoning than their siblings.
 - These mean scores also were significantly higher for the children with Primary ACC than for their siblings.

- **Perseveration (difficulty in stopping incorrect behavior):** Almost one half (about 47 of 100 or 47.3%) of children with ACC perseverated on learning tasks compared with only about 6 in 100 (5.7%) of the siblings. Comparison of sibling pairs show that the children with ACC have a significantly higher mean score for perseveration than their siblings.
 - These mean scores also were significantly higher for the children with Primary ACC than for their siblings.

- **Difficulty staying on task when learning:** Almost 60 in 100 (59.1%) of children with ACC showed difficulty staying on task when learning compared with only about 10 in 100 (10.3%) of the siblings. Comparison of sibling pairs show that the children with ACC have a significantly higher mean score for difficulty staying on task than their siblings.
 - These mean scores also were significantly higher for the children with Primary ACC than for their siblings.

Table 5: Comparison of Learning (Cognitive) Characteristics for Individuals with ACC and Their Siblings

	All individuals with ACC & Their Siblings (N = 189 pairs)	Individuals with Primary ACC & Their Siblings (N = 27 pairs)
Difficulty with abstract reasoning	*ACC > Siblings	*ACC > Siblings
Perseveration (difficulty in stopping incorrect behavior)	*ACC > Siblings	*ACC > Siblings
Difficulty staying on task when learning	*ACC > Siblings	*ACC > Siblings

*ACC > Siblings = Individuals with ACC had scores significantly higher than their siblings

Implications

- **High tolerance for pain** could result in greater chance of injury without child with ACC realizing injury. Parents may be suspected of neglect or abuse if professionals diagnosed injuries that were undetected by the parents.
- **Feeding problems (poor sucking reflex, chewing and swallowing problems):** Infants may not breast feed or bottle feed successfully, causing inadequate nutrition and hydration for the child and stress for the parent. Children who have difficulty with chewing and swallowing may be perceived as picky eaters or struggle to maintain adequate physical growth.
- **Less developed motor skills and self-help skills:** Children with less adequate self-help skills may require more time and energy for basic living skills (dressing, personal hygiene). If they lack good motor coordination, peers may prefer not to interact with them as skill in sports and hobbies/interests that require good motor coordination become important for older children.
- Children who are **moodier, have more social difficulties, or show autistic-like behaviors** may have difficulty making and keeping friends. These social challenges, combined with some of the motor and self-help skill challenges, may result in greater social isolation for children with ACC.
- Children who **perseverate (have difficulty stopping incorrect behavior)** or who show **difficulty staying on task when learning** may be perceived as challenging in schools. They may need closer attention from teachers or even assistance from aides in a classroom. The challenges of poor **abstract reasoning** increase as children move to the later elementary grades and into middle and high school curricula where abstract reasoning skills are increasingly important.

Limitations and cautions in interpreting these data

- These data represent milestones and behaviors that were reported by parents or other informants rather than observed directly.
- We have no independent measure of ACC and the presence or absence of other conditions. We relied on reports of parents or other informants.
- It is important to state again that these data represent some children who were reported to have only ACC as well as many children who have ACC and other concurrent conditions. We must be cautious in interpreting that the challenges faced by these children with ACC are due specifically to ACC rather than to some other condition or to a combination of ACC and the other conditions. We did try to identify a sub-group of children with Primary ACC. In the data where the differences still exist when compared with their siblings, we may be somewhat more confident that the differences may be due to ACC.
- In some of these variables, especially the social behaviors, the differences between the children with ACC and their siblings are small.

- These data represent first steps in trying to understand the effects of ACC on individual development. As we understand the effects more clearly, the next step will be to determine how best to help individuals with ACC use their strengths and compensate for challenges.