Sotos Syndrome and Stuttering: A Survey
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ABSTRACT
71 persons responded to a survey examining the speech traits of individuals with Sotos syndrome. Results indicate that stuttering is more common in those with Sotos syndrome than the general population. In addition, the incidence of stuttering between genders does not follow the same trend as in the general population, and a significant number of Sotos individuals with speech pathologies are not receiving appropriate speech therapy.

BACKGROUND
Stuttering is a speech disorder characterized by repetitions, prolongations or abnormal stoppages of sounds and syllables in the normal flow of speech. Stuttering may be caused by genetics, other speech and language delays or family dynamics. It is estimated that 0.72% of the general population stutter, with the highest percentage rates in younger children. Stuttering is also more common in males, with a ratio of males to females of 2.3:1. Stuttering may be treated or improved with speech therapy for fluency.

Sotos syndrome is a rare genetic disorder characterized by a particular facial shape, accelerated rate of growth in childhood, advanced bone age and frequently mental retardation. The IQ range is wide, ranging from 20 to 120. Infants and children with Sotos are also hypotonic, but will overcome this feature by adulthood, outgrowing any motor disabilities. However, social and learning disorders are common and persist into adulthood.

An additional trait seen in Sotos syndrome is delayed onset of speech and language impairments. In particular, Ball, Sullivan, Duley, Stading and Schaefer (2005) found that fluency impairment – or stuttering – is more common and has a later onset in Sotos individuals than in the general population. As there has been little research done in the area of speech pathologies associated with Sotos syndrome, the purpose of this survey was to examine the area of fluency impairment, where the unusual trends mentioned above have been observed.

METHODS
Participants
• Members of the Sotos Syndrome Support Association (SSSA) voluntarily participated in this survey.
• Upon approval by the SSSA board of directors, IRB approval was received. This indicates that procedures established at UNMC for protection of human subjects were followed.
• Fifty one of respondents reported that the affected person had been diagnosed with classical Sotos Syndrome (70.8%), 18 were diagnosed as Sotos-like (25.0%) and 3 had an uncertain diagnosis (4.2%).
• 44 individuals were male, 28 were female (ratio of males to females of 1.6:1).

RESULTS
Prevalence of Stuttering By Diagnosis

![Prevalence of Stuttering By Diagnosis](image)

**Chi-square (χ²):** 15.127 (1), p=0.002

Therapy Received by Participants who Stutter

![Therapy Received by Participants who Stutter](image)

**Chi-square (χ²):** 0.547 (1), p=0.48

**Participants**
- **Male**
  - 146 (98.5)
  - Age Range (months)
  - Classic Sotos: 26-454
  - Sotos-like: 20-62
  - Uncertain diagnosis: 5%

**Female**
- 143 (93.3)

**Age of Stuttering Onset**

![Age of Stuttering Onset](image)

**Chi-square (χ²):** 15.127 (1), p=0.002

**Stuttering Among 3 Age Groups**

![Stuttering Among 3 Age Groups](image)

**Chi-square (χ²):** 2=0.053 (1), p=0.819

**Procedures**
• Surveys were mailed to a total of 328 SSSA members. Seventy-two surveys were returned (22.0%).
• Participants completed the following survey and results were analyzed using SPSS.

**DISCUSSION**
1. There appears to be a higher tendency for Classic Sotos individuals, and then the Sotos-like individuals, to stutter (42% of Classic stutter versus only 31% of Sotos-like).
   • However, there is no significant relationship between diagnosis and stuttering (χ²=0.547 (1), p=0.46).
2. A considerable difference can be observed between the average ages of stuttering onset between Sotos individuals (81 months) and the general population (24 months).
3. A considerable difference can be observed in the percentage of those who stutter in 3 age groups between Sotos persons and the general population.
   • 0-60 months: 0% Sotos stutter vs. 1.44% of general population.
   • 61-120 months: 43% of Sotos stutter vs. 0.53% of general population.
   • 121+ months: 50% of Sotos stutter vs. 0.53% of general population.
4. As stated previously, the population average of prevalence of stuttering between genders is a male to female ratio of 2:1. Our ratio was 1:1.
   • Unlike the general population, there is no significant difference in prevalence of stuttering between the two genders in individuals with Sotos syndrome (χ²=0.053 (1), p=0.819).
5. A significant difference exists between those receiving appropriate therapy and those who are not (χ²=15.127 (1), p=0.002).
   • Fluency therapy is the appropriate therapy for persons who stutter.
6. Many of those who stutter (36%) are receiving speech therapy for articulation or vocabulary rather than for fluency.

**IMPLICATIONS**
1. There is a greater prevalence of stuttering in individuals with Sotos syndrome than the general population. In addition, the average age for onset of stuttering is much higher.
2. This requires speech-language pathologists, teachers and parents to be aware that those with Sotos syndrome need to be screened for stuttering even as old as 12 years. These individuals may then receive appropriate speech therapy.
3. There are many Sotos individuals receiving speech therapy for articulation and vocabulary. Parents and professionals need to be aware that those with Sotos syndrome may have such vocabulary and articulation problems. All needs should be addressed in these individuals.

**REFERENCES**

**SOFTWARE**