

Rare infant seizure disorder often missed

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(HealthDay)—Many infants with a rare form of epilepsy known as infantile spasms aren't promptly diagnosed, and that delay can lead to devastating health consequences, new research indicates.

The peculiar clusters of seizures usually strike between 4 and 12 months of age, said study researcher Dr. Shaun Hussain. He is an assistant professor of pediatrics at the University of California, Los Angeles.

"It is completely different from other types of seizures," Hussain said. They last about a second. Typically, the child drops his head and jerks his arms up. Parents may not notice or might think it's nothing to worry about, the researcher said.

But untreated, "[infantile spasms](#) lead to terrible outcomes," said Hussain, who's also director of the UCLA Infantile Spasms Project.

These outcomes can include autism, lifelong epilepsy or mental retardation, he said. Even a delay of a week in getting a diagnosis and treatment may lead to a measurable drop in intelligence, he added.

For this study, Hussain and his UCLA colleagues surveyed the parents of 100 children who suffered the spasms. Nearly half waited a month or longer before getting an accurate diagnosis, the study found.

Only 29 percent of the children were seen by an effective provider within a week of the spasms' onset, the researchers found.

For some, the delay was several years. Parents' education levels, household income, insurance or other factors had no effect on the timing, the study determined.

In some cases, doctors and pediatricians didn't recognize the condition and discounted parents' concerns, Hussain's team found.

The parents themselves frequently came up with the diagnosis using sources on the internet.

The subtle spasms can be confused with common childhood problems such as colic, said Dr. Amy Brooks-Kayal, chief of pediatric neurology at Children's Hospital Colorado.

She and Hussain said infantile spasms can be diagnosed with video EEG (electroencephalography). This refers to 24-hour or overnight monitoring to track and record [brain wave patterns](#).

"If parents are worried, they should request to see a pediatric neurologist for a video EEG and ask that their primary care provider facilitate an urgent appointment so that the child can be seen quickly," said Brooks-Kayal. She wasn't involved in the study.

"The usual recommendation is less than two weeks," she said.

With this new report, Brooks-Kayal added, "something that has been long suspected has been quantified."

The infantile seizure disorder strikes about one in 2,500 infants in the United States, according to the study authors. Various brain abnormalities, injuries and damage from stroke or infection can bring on the seizures, Hussain said. In many cases, doctors can't find a clear cause.

Often, a chaotic brain wave pattern known as hypsarrhythmia accompanies the spasms. The cumulative effect of this combination may be even greater damage, according to Hussain.

Treatment for infantile spasms includes antiepileptic medicine or hormonal therapies. However, these have side effects and don't always work, Hussain said. Some children may need surgery.

Hussain presented his findings this week at the American Epilepsy

Society annual meeting, in Houston. Data and conclusions presented at meetings are usually considered preliminary until published in a peer-reviewed medical journal.

More information: To learn more about infantile spasms, visit UCLA's [Infantile Spasms Project](#).

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