Epilepsy diagnoses in Norwegian children were wrong one-third of the time

Epilepsy is the most common chronic neurological disease in children, affecting between 0.5 to 1 per cent of all children.

In a newly published analysis of epilepsy diagnoses in Norwegian children, however, fully one-third of children had been incorrectly diagnosed, as reported by the Norwegian Institute of Public Health (FHI) and colleagues in a study recently published in the journal Pediatrics.

"It's scary that there are so many people who seem to have received a diagnosis of epilepsy without actually having the disease," said Henrik Peersen, General Secretary at the Norwegian Epilepsy Association, in response to the findings.

"We have long suspected that there are errors in the diagnosis of epilepsy," he added. "But this can cause problems the other way, in as much as children may not be properly investigated to see if they have epilepsy."

A rich database provides clues

The researchers used data from the Norwegian Mother and Child Cohort Study. The cohort study includes questionnaires that were regularly filled out by mothers with children born between 1999 and 2009. The questionnaires asked mothers about many different illnesses, including epilepsy.

The study population included 112,744 children from the cohort study who were aged 3 to 13 years at the end of follow-up by the registry on 31 December 2012. The researchers then compared information on these children with the questionnaires filled out by their mothers and to diagnoses that were recorded in the Norwegian Patient Registry.

After the diagnoses had been quality checked, the researchers found that one-third of the children did not meet the criteria for an epilepsy diagnosis. Only 587, or 65.6 per cent, of the 896 children who were either reported or recorded as having epilepsy actually had the disease, according to its classical definition.

"Three-hundred and nine children were recorded as having a diagnosis of epilepsy, even though they did not meet the criteria," said Kari Modalsli Aaberg, a pediatrician at the Norwegian Institute of Public Health who was head of data collection for the study and its first author.

The classic definition of epilepsy that applied during the study period is that the child must have had at least two unprovoked epileptic seizures at least 24 hours apart.
“It appears that there is a low threshold for referring children to be checked for epilepsy in Norway. The high number of unconfirmed diagnoses may be the explanation for this,” Aaberg said.

**Coding errors and different types of seizures**

The researchers think one reason so many children had the wrong diagnosis might be from incorrect coding in the Norwegian Patient Registry.

Most of the children who did not meet the criteria for epilepsy had experienced other kinds of seizures, such as those caused by high fevers, or related non-unspecific episodes of “being absent” or other neurological or developmental disorders.

"The study shows that epilepsy can be a difficult diagnosis to make in children," says Aaberg.

She said, however, that it is important to have correct figures on the occurrence of epilepsy in order to plan follow-up of these children.

**Unclear how some diagnoses were made**

One-third of the children in the study had received a tentative diagnosis by a clinician during an investigation of suspected epilepsy. One-third had been diagnosed after an EEG examination (examination of the brain's electrical activity).

“When a doctor makes a diagnosis of epilepsy, he or she is required to contact the specialist health service. In many of the patient journals we found a question mark next to epilepsy, which showed that the doctors thought the diagnosis was tentative. The code for epilepsy was used not only in confirmed cases of epilepsy, but also in some children diagnosed with suspicion of epilepsy,” Aaberg said.

Many of these children were found to not to have epilepsy during a subsequent investigation, so that the clinical conclusion was then that the child did not have epilepsy.

But the researchers were unable to find out where or from whom the diagnoses came for just under a third of the children.

**Some children given medications for no reason**

Among the 309 children who were incorrectly diagnosed with epilepsy, 57 of them had been given epilepsy medication. The parents of these children were informed of the diagnosis, but the researchers interviewed only 60 per cent of the parents. Therefore, they do not know how many parents in total thought their child had epilepsy even though the child did not.

"Those who were medicated accounted for 18 per cent of the children who were mistakenly diagnosed. These may have been children for whom the suspicion of epilepsy was strong, but that later turned out not to have epilepsy,” Aaberg said.

The study was a collaboration between the Norwegian Institute of Public Health, Oslo University Hospital, the Akershus University Hospital, University of Bergen, University of Edinburgh and Royal Hospital for Sick Children in Edinburgh.

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One in three children in Norway who have been diagnosed with epilepsy did not actually have the disease, according to a newly published study in the peer-reviewed journal Pediatrics. (Photo: Shutterstock/Scanpix/NTB)

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