

## Newborns, infants and epilepsy – the missing piece of software

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### Abstract

Diagnosing epilepsy on a small child is a challenge. A child's brain undergoes tremendous changes during the first years, creating new neural connections every second. It follows from this that what the parents and the physician may regard as abnormal behavior, can be perfectly normal. However, in some cases the abnormal behavior may be caused by epilepsy. In that case, either a detailed description of the seizure or, preferably, an eye-witness' recording of it is invaluable in terms of making an accurate diagnosis. Naturally, an EEG is also needed. Obtaining relevant, detailed information from parents is not always a straightforward matter. In order to enable collecting more accurate information about episodes that are potentially epileptic, new practices and technologies are needed. In the following viewpoint we present what can be called the missing piece of software.

**Keywords:** epilepsy

### Briefly on infant seizures

A new child is a bundle of joy and anticipation. Understandably, any illness that a child may have is distressing for parents and family. Particularly neurological disorders, such as seizures of unknown origin, are a bane for any parent. There are many causes for seizures in small children, the most common being genetic, structural or metabolic. However, seizure classification and etiological investigations are often a challenge as small children differ significantly from adults. In classifying seizure types and diagnostics of epilepsy, issues such as duration and evolutions of signs are important (Table 1).

Often these kinds of seizures, especially if they are epileptic, come without a warning. They may occur at home or even during sleep. During a seizure, the parent's focus is on the child's vital signs, and observing of ictal signs, i.e. particulars of the seizure, is difficult. Questions on the details about eye movement, or muscle tone, etc. are often left unanswered.

Epilepsy diagnosis is based primarily on the semiology of the seizures and the clinical examination of the child. In the hospital, the most important information for the diagnosing physician, pediatrician or child neurologist, is a detailed description of the seizure. The general rule of thumb is that the more detailed the description is, the better.

A detailed description of the seizures is necessary, as a non-epileptic phenomenon may be difficult to distinguish from actual epileptic seizures. In infants and small children, such seemingly abnormal behavior may include e.g. fifth-day-fits, Sandifer syndrome, tantrum attacks, different forms of dyskinesia, head nodding, self-stimulation, or titubation.

### Documenting seizures

Information about these kinds of seizures is best documented with a good quality video, recorded safely on-site (in other words, at home, playgrounds, etc.). The recording can be used together with results from EEG and brain MRI examinations in order to classify seizures and find out the most appropriate diagnosis and treatment of the child. Over a longer period of time, the recordings are also of the essence in understanding how the seizures and symptoms have changed and what is the current clinical state of the patient.

Today's parents of a small child are, in general, experienced technology users owning a modern smart phone. So, from the perspective of a parent, documenting (i.e. video recording) a seizure is rarely a technological challenge. All in all, there are different challenges to overcome, and while some of these are related technology or use of it, others are not.

**Table 1.** Some of the factors observed during an epileptic seizure.

Factor	Description
<b>Level of Consciousness</b>	Normal or impaired, loss of consciousness, absence.
<b>Motor signs</b>	Tonic, clonic, tonic-clonic, atonic, myoclonic.
<b>Sensory signs</b>	Visual, auditory, smell, etc. sensations
<b>Autonomic signs</b>	Pallor, automatisms, drooling, vomiting, palpitation, sweating, urination, defecation, etc.
<b>Localization of signs</b>	Bilateral, unilateral, symmetric, asymmetric
<b>Duration of signs</b>	Single or repeated
<b>Evolution of signs</b>	Change of signs during a seizure
<b>Postictal symptoms</b>	Symptoms that occur after the seizure

First of all, documenting a seizure is not easy. The need for taking a video may occur suddenly, without any warning, and it may last only few seconds. For example, in atonic seizures where muscles suddenly lose their tone, a seizure can manifest itself in the form of a simple head nod. In practice, documenting this kind of seizures requires luck – or prolonged periods of recording.

Secondly, if a seizure is caught on a video, it does not mean that it is *well-documented*. In addition to good technical quality of the video, good documenting calls for two basic functions that are not always available (or easy to use) even on a modern smart phone: 1) editing, and 2) commenting. In order to clarify what kind of behavior the parents consider to be abnormal or epileptic of their child, video editing and clarifying comments, linked to specific events on the recording, are needed.

### The missing piece

Even if a seizure has been recorded and well-documented, the later use of the video is often a problem. As the recording now contains patient information, it should be treated accordingly. Basically, this means that the recording, and the accompanying comments, should be sent to the responsible physician or other health care professional in a secure fashion. This in itself is already a problem as 1) the assigned professional is not always known to the parents, and 2) there are often multiple professionals involved in the care of a small child with neurological symptoms.

In addition, even if the recording reaches the intended recipient in a secure fashion, there are often problems with the playback as it is often unfeasible to install (and update) different video codecs or applications on the health care professional's workstation. Moreover, even if this is achieved, the health care professional should be able to integrate the recording into the electronic

health record of the patient for later use. This entirety, reusable and integrated document on patient seizures, is what we call the *missing piece of software*.

### Final remarks

What we are calling for is more than a piece of software. If this kind of an arrangement for recording seizures is implemented, educating is needed on two levels. 1) The health service providers need education on how this kind of information that is not created during a clinical encounter could and should be used in decision-making. 2) The parents of a small patient need education on how a well-documented recording is made without compromising the child's safety during a seizure.

However, if this kind of a solution is implemented and taken into day-to-day clinical use, it may have additional benefits. The documented seizures, linked in the form of a longitudinal digital patient record, such as the one used in Finland, can provide new information on the evolution epileptic seizures and health of the child. More so today, as Artificial Intelligence (AI) is reshaping the field of healthcare.

### Disclaimer

*The discussion above is based on observations made during a meeting by the Finnish Epilepsy Association (FEA) in 2015. In the meeting, 10 families with a child who has been diagnosed with epilepsy, and 3 members of the association, discussed on the current state of care in Finland, and challenges they have encountered. In the meeting, a solution that could be used for reporting epileptic seizures was considered to be of importance especially in two cases: 1) when the diagnosis is new or uncertain, and 2) if the type of seizures change (for example, due to change in pathology or medication).*