A 13-Month-Old Male with Possible Seizures
Robert Listernick, MD

A 13-month-old male was admitted for evaluation of possible seizures. Several days prior to admission, while awake, his limbs suddenly stiffened and his eyes had a “glazed look.” This lasted for approximately 1 minute, followed by generalized shaking of his limbs that lasted 40 seconds. He returned quickly to baseline. Two days later he had a similar episode, after which his temperature was measured to be 101.6 °F. His mother took him to an outside emergency department where he had a normal computerized tomography scan of the head, and then was transferred here. Of note, his mother reports that he has always had a large head circumference.

Review of systems was negative. His weight was 1.8 kg after a 32-week gestation. The pregnancy was complicated by bleeding throughout the pregnancy but no etiology was determined. Membranes were ruptured 4 days prior to delivery. He spent 14 days in the neonatal intensive care unit. During that time, he was jaundiced and received phototherapy without any major complications.

His medical history is remarkable. He was diagnosed sometime in infancy as having plagiocephaly and has been wearing a helmet since then. He is under-immunized, although I have no information as to why. The family history was unremarkable for any member with seizures or neurologic abnormalities. Developmentally, he learned to crawl at 10 months, and at present says only “mama” and “dada.” He does not walk.

On examination, he was alert and obviously macrocephalic. Weight was in the 15th percentile, length in the 20th percentile, and head circumference in the 90th percentile. He had right-sided plagiocephaly with an abnormally shaped cranium that was disproportionally large compared with his body. General physical examination was normal. On neurologic examination, he was alert and interactive with slightly decreased truncal tone. Reflexes were 2+ bilaterally. Muscle strength was normal throughout. He could not stand unsupported but did sit unsupported and was able to crawl.

Robert Listernick, MD, moderator: How should we evaluate this child who has had two seizures, one of which was afebrile?

Srishti Nangia, MD, pediatric neurologist: He is an ex-premature infant who is clearly globally developmentally delayed, hypotonic, and macrocephalic. Two seizures in the setting of an acute illness suggest the possible unmasking of epilepsy. We should consider the causes of macrocephaly and seizures.

Dr. Listernick: Suppose this were a first unprovoked seizure in a neurologically normal child?

Dr. Nangia: The American Academy of Neurology Practice Parameter recommends the performance of an electroencephalogram (EEG) to predict the risk of recurrence and to classify the seizure type and epilepsy syndrome. All other testing, including neuroimaging, should be performed only based on the specific clinical circumstances.

Dr. Listernick: The EEG was mildly abnormal because of rare, single focal interictal epileptiform discharges at the frontal central vertex and right frontal central area during sleep. Can you translate that for the uninitiated?

Dr. Nangia: Although this is a focal abnormality, it is a relatively nonspecific finding. This could be seen in children with typical febrile seizures or those who have neurostructural pathology. Given the focality in this child who has abnormal development and an abnormal exam, neuroimaging is warranted.

Dr. Listernick: The magnetic resonance imaging (MRI) exam showed mild prominence of the lateral and third ventricles without temporal dilatation. There was normal myelination. There were small foci of hemosiderin at the right corticothalamic groove as well as additional scattered foci of signal change in the periventricular and subcortical white matter. These findings were sug-
gestive of mild perinatal ischemic injury.

Leslie Finkel, MD, pediatric neurologist: We felt that the MRI was suggestive of perinatal ischemia. However, review of the pediatrician’s records definitely showed progressive macrocephaly with the head circumference crossing percentile lines. Given that he didn’t have hydrocephalus or a mass, we considered the possibility of diseases that would cause developmental delay and macrocephaly, such as Alexander’s or Canavan’s disease. The normal myelination pattern for age mitigated against these diagnoses, but we did send testing for whole genome microarray, Fragile X syndrome, and some of the mucopolysaccharidoses.

Dr. Listernick: He was started on levetiracetam because of the combination of his history and the mildly abnormal EEG. We felt that the story was very reasonable for seizures. The following tests were normal: complete blood count, serum chemistries, ammonia, lactic acid, acylcarnitine profile, urine organic acids, urine glycosaminoglycans, Fragile X testing, whole genome microarray, and urine oligosaccharides. Over the next several months his seizures were not well controlled on levetiracetam, so phenobarbital was added to the therapeutic regimen.

Dr. Finkel: I would receive twice weekly calls from his mother that he was vomiting the medication. It is difficult to check levetiracetam levels and it has a narrow therapeutic range. So, we decided to taper off the levetiracetam and try phenobarbital, which is easier to monitor.

Dr. Listernick: The episodes of vomiting increased, leading to several emergency visits and hospital admissions. It was felt that he was unable to keep his medications down due to the vomiting, which was leading to increased seizure frequency. In addition, he had several episodes of hematochezia without a major drop in his hemoglobin concentration.

Jacob Kurowski, MD, pediatric gastroenterologist: There was never any hematemesis in the hospital. In addition, he continued to grow and gain weight on his established curve; there wasn’t any concern that the vomiting was having a huge impact on his nutritional status. We considered several possibilities as the etiology for his chronic vomiting, such as eosinophilic esophagitis, allergic gastroenteritis, or even metabolic disease. Gastroparesis was also a consideration but the history really was not consistent with this diagnosis; when his mother tried to give him medications, he reflexively vomited. It seemed very behavioral in origin. However, we did perform upper endoscopy to eliminate some of the diagnoses I described, and it was entirely normal. Barium examination of the upper gastrointestinal tract was normal except for several episodes of gastroesophageal reflux; there was no evidence of a disorder of intestinal rotation. Gastrostomy tube placement was considered, primarily so he could receive his medications.

Anthony Chin, MD, pediatric surgeon: Children are referred to us for gastrostomy tube placement consultations for many reasons, including non-compliance with medication or nutritional supplementation, inability to take seizure medications, poor weight gain in neurologically abnormal children, and poor weight gain in neurologically normal infants who have feeding disorders. I always discuss the risks and the benefits of the gastrostomy tube and the different options to gastrostomy tube insertion, including nasogastric tubes, gastrojejunal tubes, or jejunal tubes. Frankly, I usually encourage the use of nasogastric tubes. Parents often feel that gastrostomy is a panacea to solve all of their child’s problems; I want to disabuse them of that notion. I usually perform laparoscopic-assisted gastrostomy tube insertion.

Dr. Listernick: What about Nissen fundoplication?

Dr. Chin: I always discuss this option for vomiting patients but we, as an institution, try to avoid them initially.
They have a 5%-10% rate of slippage in infants.

Dr. Listerick: What are the potential complications of gastrostomy tube insertion?

Dr. Chin: Leakage around the tube, burning of the abdominal wall by gastric acid, granulation tissue formation, stomach perforation, intestinal perforation, and the tube “popping out.” I try to make the family aware of all these possible complications. Although most often everything goes well, these complications can be quite frustrating for parents.

Dr. Listerick: What happened over the next several months?

Dr. Chin: I left the invitation open to call me back and return to discuss a future date for gastrostomy placement. The child continued to vomit and not receive his medication. There was a discussion about placing a nasogastric tube but the mother really wanted the surgery. Ultimately, the gastrostomy tube was placed. There were sporadic reports of vomiting during the hospitalization when the gastrostomy tube was placed, but ultimately he did well and was sent home. By history, he continued to vomit medication at home, although there was no problem with feeding. We changed the tube to a gastrostomy-jejunostomy (GJ) tube so that the child could receive the medication jejunally. Sometime in the midst of this, he developed rotavirus gastroenteritis, which complicated his illness and was getting all his information from the mother; he had no idea what was happening. The other fact we learned was that the parents had recently paid closer attention to the documentation of the vomiting—who witnessed it, when did it occur, were any health care personnel present, etc. This need to complain of emesis when medical staff was not present.

Throughout these latter admissions there had been an ongoing concern for medical child abuse.

Dr. Listerick: As the late-night hawker on television say “But wait, there’s more!” The patient was readmitted twice; first, several days later with hematemesis and seizures to an outside hospital, and finally here due to gastrostomy tube leakage. The mother said that the child had pulled out the tube. When it was examined closely, there were two small holes in the balloon. Throughout these latter admissions there had been an ongoing concern for medical child abuse, and the protective services team became involved.

Kristine Fortin, MD, MPH, protective services physician: One key fact that we learned early in the evaluation was that the father only speaks Spanish and was getting all his information from the mother; he had no idea what had been happening. The other fact we learned was that the parents had recently separated, and the mother clearly stated that it was her goal to get back together with the father; when the child was in the hospital they spent a lot of time together.

Dr. Listerick: Is this Munchausen syndrome by proxy?

Dr. Fortin: We now prefer the term “medical child abuse.” Munchausen syndrome by proxy implies a diagnosis of a parent, whereas “medical child abuse” focuses on what’s happening to the child and that he’s receiving unnecessary medical care at the instigation of the caregiver.

Dr. Listerick: Is there a common scenario in which we might see medical child abuse?

Dr. Fortin: Yes, but as in any form of child abuse, it could happen in any family. Statistically, the mother is far more likely to be the perpetrator. I’ve actually never seen a case where the father was the perpetrator. The mother is often part of the health care system or has received some form of health care training. The father is often absent or traveling a great deal for his job. Finally, there is often a history of psychiatric illness in the family.

Dr. Listerick: How can we learn from our mistakes looking at this case?

Dr. Fortin: The common patterns I look for are when facts don’t add up—you’re being told one thing but the child appears differently; information doesn’t make sense medically; there are odd patterns of equipment failure, etc. Often, the child has seen multiple providers at multiple institutions. It’s extremely important to get all the records so you know all the facts, rather than relying on what the parent tells you. It can be extremely time consuming.

Dr. Kurowski: We really should have paid closer attention to the documentation of the vomiting—who witnessed it, when did it occur, were any health care personnel present, etc. This started to come to light when the nurses on our floor began talking directly to the nurses on the neurology floor; common patterns were observed, specifically that the nurses never actually witnessed the
emesis, just the after effects with the dirty towels the mother used to “clean up the mess.”

Dr. Listernick: Can covert video surveillance (CVS) be used in establishing the diagnosis of medical child abuse?

Joel Frader, MD, pediatric ethicist: We have the capacity and policy support for CVS here, under appropriate circumstances. The question is: what are the appropriate circumstances? There are no standards for undertaking CVS. There are differences in state laws; in some states you need a court order for CVS. Our hospital policy permits CVS only after the child abuse pediatricians confer with others in the institution and decide that surveillance is necessary. We require someone to observe the video feed at all times, so we have the capacity to intervene if a life-threatening event, such as an attempted smothering, occurs.

Dr. Listernick: Do you have concerns about its use?

Dr. Frader: I think CVS may be the only alternative under certain circumstances to protect the health, and sometimes the life, of the child. However, we need to take great care in coming to the conclusion that we must use CVS—it does impinge on the parents’ usual expectation of privacy. We should remember the legal and ethical principle that enjoins us to use the least restrictive/invasive alternative available. CVS should be the last resort in an investigation and done under the guidance of child abuse experts. CVS should never be a primary investigative tool.

Dr. Fortin: With that in mind, we’ve been quite successful in having objective sitters in the room, which allows for clear documentation of events. One of the harder parts of this case was that this child does have a clear-cut medical problem (seizures), which led his physicians both here and at the outside hospitals to take the complaint of vomiting more seriously.

Dr. Listernick: What was the final outcome?

Dr. Fortin: For the moment, the child is in the care of his paternal grandparents and the mother is to have no contact with him. The investigation is ongoing. Often, the hardest aspect of these cases is convincing the state authorities of the ongoing potential for harm, as the parents often seem nice and upstanding.

Dr. Listernick: Thanks everyone.

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**Key Learning Points**

1. In children who have a first unprovoked seizure, the American Academy of Neurology Practice Parameter recommends the performance of an electroencephalogram to predict the risk of recurrence and to classify the seizure type and epilepsy syndrome. All other testing, including neuroimaging, should be performed only based on the specific clinical circumstances.
2. Medical child abuse is defined as a situation in which the child is receiving unnecessary or harmful medical care due to the instigation of a caregiver.
3. The perpetrator of medical child abuse is generally the mother. Often she has had some form of health care training.
4. Covert video surveillance should be a method of last resort under the guidance of child abuse experts rather than a primary means of investigation.