“What we’ve got here is failure to communicate”: The Value of Reassurance

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A 2-year, 8-month-old boy was sent to the hospital by his pediatrician for an inpatient workup of fever of unknown origin. The child was born full term, had a normal newborn course, and was a healthy infant until he had a fever at 3 months of age due to influenza diagnosed by rapid in-office testing. This illness was managed as an outpatient, and the fever resolved after 2 days. However, the pediatrician did place emphasis on fever height and frequency as a sign for severe illness, such as meningitis, indicating a need for possible hospitalization and additional testing. He was again evaluated for fever in the emergency department (ED) at 8 months of age, and the ED staff confirmed a fever of 38.5°C. During that visit, he was diagnosed with an acute viral illness after laboratory testing resulted negative and discharged from the ED. Later that month, he was referred to gastroenterology for vomiting and fussiness, diagnosed with gastroesophageal reflux disease, and prescribed both lansoprazole and simethicone.

At 10 months of age, he was taken to the ED because of continued fussiness; an abdominal ultrasound and urinalysis were obtained, both of which were normal. The child’s pediatrician obtained an upper gastrointestinal series later that month, which demonstrated normal anatomy. He was started on both erythromycin and bethanechol for worsening gastroesophageal reflux disease. Weeks later, he was taken to his pediatrician for 7 days of fever. A chest radiograph was obtained and deemed normal. At that point, he was admitted for fever of unknown origin. Temperatures were taken every 4 hours during the 2-day inpatient stay, and all were within normal range. Diagnostic workup included blood and urine cultures, C-reactive protein, Bartonella immunoglobulin (Ig)G and IgM, Epstein-Barr nuclear antigen IgG and IgM, and cytomegalovirus IgG and IgM. Each test was negative and his complete blood count was normal. The child was discharged from the hospital with the diagnosis of a viral illness, and the family transferred the child’s care to a new pediatrician later that month, citing location preference as the reason for transfer.

Over the next 22 months, the patient was taken to his preferred care provider (PCP) or to the ED at least 11 times for chief complaints of fever, nasal congestion, or fussiness. The medical provider did not always evaluate temperatures, but each temperature that was taken was normal. During this time period, his providers obtained anterior-posterior and lateral neck films, a urinalysis, an abdominal ultrasound, and at least 4 rapid strep tests. All were negative except 1 rapid strep test that was positive.
Despite being afebrile and lacking any abnormal physical examination findings during these evaluations, the child was placed on at least 7 courses of oral antibiotics and 1 course of oral steroids. He was referred to otolaryngology for tonsillectomy after receiving 4 courses of antibiotics within 1 month for pharyngitis. Insertion of bilateral pressure equalizing tubes was also performed during the operation, despite the child having had only 1 documented episode of acute otitis media. He was again referred to an ear, nose, and throat specialist for frequent snoring and recurrent diagnoses of sinusitis, and an adenoidectomy was performed.

When the child was 31 months old, his PCP saw him 3 times within 1 month for evaluation of fever. The PCP obtained a complete blood count, comprehensive metabolic panel, C-reactive protein, serum IgA, IgG, IgD, IgM, and IgG subclasses, rheumatoid factor, erythrocyte sedimentation rate, antinuclear antibody, and respiratory viral panel, all of which yielded normal or negative results. The pediatrician then planned to refer the child to a pediatric infectious disease specialist. When the child was taken to the office a fourth time in the same month for fever, the physician immediately admitted the child to our hospital for evaluation of fever of unknown origin.

Upon arrival to the hospital, the child was afebrile, had an entirely normal physical examination and growth parameters, and was meeting all developmental milestones. The inpatient team requested the child’s entire medical record from the pediatrician, and, given the complex history and thorough workup preceding the admission, the child’s rectal and axillary temperatures were monitored every 4 hours for the first day of the admission without further workup. After recognizing that all of the temperatures were within normal range in a child with normal parameters of growth and development, forensic pediatrics was consulted because of the possibility of the diagnosis of medical child abuse. After speaking in great detail with both the child’s pediatrician and the child’s caregivers, it was found that the parents were strictly adhering to the advice of their pediatrician by checking rectal temperatures and following up for recurrent fever. The caregivers were also occasionally adding a degree to the actual temperature based on one of his grandparent’s recommendations. The “fever phobia” that started at the child’s original influenza diagnosis as well as frequent laboratory and radiologic testing had perpetuated this cycle of continuous office and ED visits for fear of serious illness. It is also important to note that the child’s mother and his grandparents seemed naturally concerned about the child and were not receiving any recognizable secondary gain from the child’s perceived condition.

The hospitalist team, with assistance from our infectious disease and forensic pediatric experts, ultimately diagnosed this patient with vulnerable child syndrome. The family was given a set of distinct instructions regarding the patient’s medical care, including discontinuation of lansoprazole, erythromycin, and bethanechol. The family was also instructed to abstain from taking any temperatures at home and provided with information on normal childhood illness patterns. They were agreeable to this plan of care and were given reassurance regarding the benign nature of common childhood viral illnesses, which may be accompanied by fever, along with the benign nature of fever itself. The child’s pediatrician was also given a copy of the plan and agreed to assist in providing reassurance to this family.

Although our local experts made the diagnosis of vulnerable child syndrome in this particular patient, it is reasonable to acknowledge that other experts might disagree and consider this a case of medical child abuse. There is significant harm caused by unnecessary testing, hospital admissions, medications, and surgical procedures, and secondary gain can be difficult to assess. Some experts believe that the vulnerable child is the stepping stone for medical child abuse, and cases of medical child abuse or illness falsification are often preceded by frequent visits to the hospital or doctor’s office earlier in life. It is important to suspect illness falsification in its early stages because cases that go unnoticed may progress to actual signs and symptoms of illness imposed on the child by the caretaker.

Vulnerable child syndrome and medical child abuse are both named entities that have existed in the literature for several years but in actuality have been around since the beginning of time. Unfortunately, we as pediatricians sometimes help perpetuate this vicious cycle. It may be tempting to prescribe antibiotics or obtain diagnostic tests on the basis of history alone. Furthermore, time constraints make it difficult to spend extra time in an office visit to reassure parents of normal fever curves and illness patterns and how these change with age. However, such behavior may cause physical harm to the patient through unnecessary laboratory testing and procedures and can potentially enable this parental delusion.

Several definitions exist for both vulnerable child syndrome and medical child abuse, also known as Munchausen syndrome by proxy and pediatric symptom falsification. Vulnerable child syndrome is described as a “set of clinical features in which unfounded parental anxiety about the health of a child resulted in disturbances of the parent-child interaction,” leading to maladaptive behaviors. One example would be a normally growing and developing child with a history of sepsis as a neonate who is brought to their PCP’s office frequently for parental concerns of weight loss, poor appetite, fatigue, or minor illnesses out of fear of serious illness. Medical child abuse, however, is more commonly considered when a “caregiver causes injury to a child that involves unnecessary and harmful or potentially harmful medical care.” There is an exception to this definition of medical child abuse when the physician is the responsible party prescribing unnecessary, low-value medical care out of ignorance or incompetence. To claim abuse, the caregiver has to be causing the inappropriate medical care to happen by misrepresented symptoms, manipulating laboratories, or purposely harming the child. Sometimes this can be difficult to prove.
Most experts agree that the risk factors for Medical Child Abuse center around a parental history of child abuse or serious childhood illness. As for vulnerable child syndrome, certain patient and parent populations are known to be at increased risk. Practitioners must maintain a high index of suspicion and recognize germane historical clues to identify those children at risk. Patients with histories of prematurity, hospitalizations, or severe illness in the neonatal period, and survival of life-threatening events are classically set up for this pathologic parent-child relationship. Our patient’s early diagnosis of influenza certainly may have initiated a “fever phobia” in the minds of his caretakers, resulting in a compulsive use of the rectal thermometer and an ultimate fabricated history of recurrent fevers for fear of serious illness. Those parents who have experienced miscarriages, infertility, or maternal illness during pregnancy are more likely to view their child as vulnerable. Likewise, parents of a deceased child are likely to overprotect a subsequent child. Our patient’s mother later disclosed that the biological father had asked for the pregnancy to be terminated. This may have been perceived as a threatened loss of the child, which is a common risk factor for vulnerable child syndrome. Particular social settings are also characteristic of children with perceived vulnerability. Those raised by single parents or extended families, as well as only children, are more susceptible to this predicament. Fittingly, our patient was an only child, raised by his mother and grandparents.

Some parents will start to present “red flags” to their pediatrician’s office, such as excessive phone calls to the office, frequent visits to the urgent care, or extreme concern over minor problems, at the start of their vulnerability. Recognizing families and patients who are high risk for vulnerability or abuse, as well as the red flags that parents might be presenting, is imperative to reduce parental anxiety and decrease the emergence of the vulnerable child and to possibly prevent abuse. Once these issues are recognized, it is important for the pediatrician to take the time to provide reassurance and extensive discussion on the variability of normal child development and to limit laboratory testing and procedures that are unnecessary. Clearly there was a dichotomy between the history of persistent fever and the clinical observation of this completely well, afebrile child, suggesting illness falsification. However, in this circumstance, our experts did not think that falsification could be definitively proven. Despite the potential for disagreement in the final diagnosis of this case, it is important to focus on how unnecessary testing and treatment can potentiate both vulnerable child syndrome and medical child abuse. As providers, we must strive toward high-value health care for our patients to avoid both physical and emotional harm.

Fortunately, with the help of our consultants in forensics and infectious disease, we were able to provide this patient’s family and primary care provider with reassurance of this normal child, educate them on normal childhood illnesses and frequency of infections, and give them a direct plan of action to deescalate parental anxiety. In our follow-up, we have learned that he is still receiving routine well-child care from the same pediatrician, but overall visits have decreased, and he has had no additional evaluations for fever.

REFERENCES