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Bundle of Misery

The Diagnosis for an Inconsolable Infant Might Be Reflux, Not Colic

Kim Fernandez Special to The Washington Post
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My son spit up the first time when he was 3 days old, jolting awake from a sound nap. The screaming started three weeks later. If Joseph was awake and not nursing, which he wanted to do constantly, he was howling, writhing and clawing at my chest with his tiny fingernails, fat tears rolling down his cheeks. After episodes that lasted anywhere from 30 minutes to several hours, he would often collapse into sleep, but only for an hour or two and only while propped up in a sitting position. On waking, the screaming started again.

Colic, the pediatrician told me over the phone when Joseph was 4 weeks old. Try Mylicon gas drops and bring him in the next morning. Her exam found nothing wrong. She told me to prepare myself for two more months of misery -- three months, she said, was the usual time allowed for colic to run its course. She was nearly out the door when she paused. "Does he spit up a lot?" she asked. He did almost every time he nursed. "It might be reflux then," she said, writing a prescription for the acid inhibitor Zantac and an order for an upper GI series test.

Her instinct was right: On the basis of the test, Joseph was diagnosed with severe gastroesophageal reflux disease (GERD), meaning that a valve in his esophagus closed improperly, allowing his stomach contents to escape. He had an almost steady stream of breast milk and stomach acid churning in his throat, which explained his pain. While Joseph's problems weren't over, he was lucky and so were we.

According to a study published earlier this year in the Archives of Pediatrics & Adolescent Medicine, GERD "is a common disease of infancy, with a prevalence as high as 18 percent in [otherwise] healthy children." What complicates the picture is that about half of all healthy infants experience twice or more daily vomiting, according to the American Medical Association. But only for some of those -- and here the count gets fuzzy -- is the upchucking accompanied by enough distress or failure to thrive to move it into the disease category. Parent activists say the condition is underdiagnosed, and there's at least some agreement in the medical community.

Last summer the North American Society for Pediatric Gastroenterology and Nutrition released guidelines to help pediatricians better diagnose and treat the disease. According to the guidelines, "gastroesophageal reflux (GER), defined as the passage of gastric contents into the esophagus, and GER disease (GERD), defined as symptoms or complications of GER, are common pediatric problems."

Left untreated, GERD can threaten a baby's health and exhaust the best-intentioned parents, provoking feelings of guilt, inadequacy and anxiety.

Andrea Dorlester, of Annandale, waited 22 months for a diagnosis while doctor after doctor said her son Daniel's frequent vomiting was more a laundry problem than a medical one. He refused solid food until he was 18 months old.

Aleeza Oshry, of Baltimore, struggled 13 months to get her often choking, gagging baby to eat before she found help; her earlier complaints, she says, were taken as signs she was lacking as a mother. "The doctor told me that I couldn' t stand him vomiting so much and that the problem was with me," she says. "He actually pointed his finger at me and said, ' That' s the problem. You' re tired of it.' "

While some cases of reflux are still misdiagnosed as colic, asthma or gagging, pediatric perspectives on the condition may be changing. One indication: more questioning of the term "colic." According to William Cochran, associate professor of pediatric gastroenterology and nutrition at the Geisinger Clinic in Danville, Pa., and chairman of the section of gastroenterology and nutrition at the American Academy of Pediatrics, colic simply refers to a baby' s crying for more than three hours a day; there is no medical definition of the term.

Bill Sears, associate clinical professor of pediatrics at the University of California, Irvine, School of Medicine, agrees. "You never accept the term ' colic,' " says Sears, the author of 27 books on child care. (When the first edition of his "The Baby Book" was published 10 years ago, it contained two paragraphs on GERD; the new version, slated for publication next year, promises to devote a 15-page chapter to the topic.) "One of the cliches is that colic is a five-letter word that means the doctor doesn' t know what' s wrong." Sears advises parents of babies who scream around the clock to tell their pediatrician "you' re not going to leave until they find out why your baby hurts."

Other experts, however, do not dismiss colic, and distinguish carefully between its symptoms and those of reflux. One of them is gastroenterologist Scott Sirlin, a former assistant professor of pediatrics at Children' s National Medical Center who is now in private practice. Colicky babies, he says, are miserable during set times of the day, typically 5 p.m. to 11 p.m. Reflux babies, on the other hand, can hurt at any time, most frequently during and after feedings.

"These are very irritable children," he says. "Unlike colicky babies, where taking them outside in a car seat or sitting them on top of a washing machine or dryer in a seat might help calm them down, typical therapeutic measures for colic are not helpful. Parents of these babies are under a lot of stress."

The "it' snot-colic" school may be growing in clout. A study published last year in the Journal of Pediatric Gastroenterology and Nutrition found that more than 60 percent of infants with colicky symptoms suffered from reflux. Cochran conducted two studies, one of children with recurrent ear infections and one of children with recurrent sinusitis, and found that a majority of both groups had reflux. Treatment for reflux, he said, ended the infections.

My son' s Zantac prescription helped, but only for a few weeks. The pediatrician tried increasing the dose and suggested several home remedies. When these didn't work, we landed at the gastroenterology department of Children' s National Medical Center.

By now, Joseph had ulcers lining his throat. Under a specialist' s care, we tried several drug combinations. About three weeks after our initial consultation, we finally hit on the right one. At about 22 weeks, Joseph slept through the night, marking the first time in many weeks that he had slept for more than an hour or two at a time.

But I' m getting ahead of myself.

When first-line reflux treatments such as acid inhibitors fail to soothe a baby, tests are often used to rule out other anatomical problems.

While a suspected GERD diagnosis for adults can be confirmed visually by

esophagoscopy -- placing a lighted tube in the esophagus while the patient is under anesthesia -- the test is considered too invasive for infants except in the most severe cases.

A more common test for babies is a pH probe, in which a small piece of tubing is placed down the baby' s throat for 12 to 24 hours to measure acid levels; no anesthesia is needed in what' s often an outpatient procedure. Another test, called a scintography, uses a computerized scan of a baby' s abdomen to see how long it takes the stomach to empty. Delayed gastric emptying -- according to one definition, where more than half of a substance remains in the stomach after 60 to 90 minutes -- can contribute to GER. In severe cases, doctors perform an endoscopy -- inserting a tube through the mouth while the baby is under general anesthesia -- to examine the esophagus, stomach and intestines to check for reflux-related tissue damage. An upper GI scan is also an option.

Joseph had his upper GI series at 6 weeks old. We skipped his normal midmorning feeding so that he would drink a bottle containing a barium solution while a camera was suspended over his stomach, and technicians and a doctor watched to see what happened. The test proved his reflux; he "refluxed" all over the table, the camera, and an ill-placed technician. But more important, the test showed that his intestines and stomach were free of anatomical abnormalities that could have caused his problems.

We had the all-clear, in other words, to see if medications we hadn' t yet tried might help.

The drugs used to treat reflux, including Zantac, Prevacid, Reglan and Prilosec, have to build up in the baby' s system for 10 to 14 days before parents can gauge if they' re helpful or not. In Joseph' s case, the first few drugs we tried after his Zantac stopped working didn' t do anything much for him. We' d start a drug, wait through two weeks of screaming, call the doctor and start another drug for another sleepless round.

Meanwhile, the strain was showing on my husband and me.

That' s often the case for families of reflux babies. Some liken the experience to living with a volcano that can erupt at any time. Going out with the baby, even for a quick dinner or to the grocery store, becomes unmanageable. Parents often find themselves terrified that their babies will choke to death when they do fall asleep -- a rare but possible occurrence -- and tune in to baby monitors instead of resting themselves. "We worry very much about the families," says Beth Anderson, who runs the Pediatric/Adolescent Gastroesophageal Reflux Association, a Germantown-based advocacy group that provides information and support for reflux families. "We' ve had parents who have been so sleep-deprived that they' ve hallucinated," says Anderson. "Parenting a child with reflux is definitely intensive-care parenting, and it' s 24/7."

Because of this, the group' s volunteers make it a point to check on parents and siblings of refluxers. "Children of reflux do try the patience of a saint," says Anderson. "Every parent we' ve talked to has admitted that they had visions of throwing the baby through the window. They were scared that they were borderline capable of doing that," she says.

Shortly before Joseph started on Prevacid, the drug that ultimately stopped his pain -- and his incessant screaming -- I left the house for an hour to get my hair cut. In the parking lot, I fantasized about running away. For about five minutes, I sat in my car and sobbed, feeling like the worst mother in the world.

Two months past his first birthday, Joseph is a happy toddler who talks and crawls and stands and smiles almost nonstop. He takes a long nap every day and sleeps through the night more often than not. He still takes Prevacid once a day. The

only way we know he still has reflux is through vomiting, though its frequency has dropped markedly. It gets worse right before a new tooth arrives.

We visit Children' s every few months for follow-up.

Aleeza Oshry' s son is now 18 months old, and she worries that his Zantac is losing its effectiveness. She' s getting ready to take him to a speech therapist -- refluxers sometimes experience speech delays. The therapist will also teach him to accept different food textures -- another thing reflux has kept him from experiencing.

Andrea Dorlester' s son, 28 months old, is struggling with eating issues as well. She' s hopeful, however, that continued treatment and working with a speech pathologist will help him overcome the problems, and she' s basking in the glow of a compliment her new family doctor gave her recently.

"He said, ' You parents are doing a good job,' " she says. "That was the first time a doctor had said to me that, as a parent, I was doing a good job."

Kim Fernandez is a Washington-area freelance writer.

Sidebar: For Parents: How to Recognize The Problem and Help Treat It

All babies are fussy at times. Spitting up and crying are two normal features of their broad distress repertoire. However, persistent prolonged occurrences -- crying that goes on for days and may interfere with feeding -- warrant a doctor' s attention.

According to the Pediatric/Adolescent Gastroesophageal Reflux Association, a Germantown-based advocacy group, possible signs of reflux in infants include the following:

- Frequent spitting up after meals, sometimes with spitting or projectile vomiting in between feedings.
- Frequent hiccups.
- Wanting to feed frequently but only for a few minutes at a time
- Acting hungry but refusing feedings.
- Arching the back during feeding.
- Sleeping in short bursts with excessive crying in between.
- Fussing after feeding.
- Hoarse voice.
- Excessive gassiness.
- Signs of abdominal pain: drawing up legs, arching back.
- Sour burps or bad breath.
- Waking from sound sleep with screaming and/or writhing
- Failure to thrive: poor weight gain, poor growth.
- Wheezing or excessive coughing.
- In older babies, resisting solid foods or holding solids in the mouth without gumming or swallowing.

Simple home strategies can also help reduce some babies' discomfort.

Some doctors recommend them to parents as an adjunct to drug therapy; others advise parents to try them in the hopes of avoiding medical interventions. Among tactics recommended to parents by pediatricians Bill Sears and Scott Sirlin:

- Thicken formula or breast milk with rice cereal. The idea here is to enlist gravity to help keep formula down.

- Hold your baby upright for 30 minutes after feeding, rocking her to minimize crying. (Excessive crying, because it involves the swallowing of more air, can aggravate reflux.)
- Offer smaller, more frequent feedings.
- Burp the baby sufficiently after feedings.
- Keep the baby away from cigarette smoke, which can aggravate reflux.
- Consider prone positioning during sleep only in consultation with a doctor and only, according to new guidelines from the North American Society for Pediatric Gastroenterology and Nutrition, "in unusual cases where the risk of death from complications of GER outweighs the potential increased risk of SIDS [Sudden Infant Death Syndrome]."

If your pediatrician suspects reflux disease and you' ve already tried home treatments without success, the doctor may prescribe one of a number of drug therapies.

The most common are: an over-the-counter antacid such as Mylanta or Maalox; acid inhibitors such as Zantac; acid blockers such as Prevacid or Prilosec; motility drugs, such as Reglan; anti-ulcer drugs, such as Carafate.

Should the problem persist, consider insisting on a referral to a specialist, advises Scott Sirlin, a Children' s National Medical Center gastroenterologist.

But there' s a problem with that approach: Because of the small pool of pediatric gastroenterologists -- by Sirlin' s count, there are only 11 in the Washington area and 900 in the nation -- the wait could be several months.

Surgery is reserved for life-threatening or severely debilitating cases: In a technique called fundoplication, doctors wrap a band of muscle around the lower esophagus to tighten the malfunctioning valve.

Resources

- Ask Dr. Sears: Enter "reflux" on search line of the Web site www.askdrsears.com, which is sponsored by pediatrician and author William Sears.
- Children' s Medical Center of the University of Virginia: http://hsc.virginia.edu/cmc/tutorials/reflux/
- The GERD Word, a Web site sponsored by the International Association of Reflux Parents: http://welcome.to/GERDWORD
- North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition: (NASPGHAN): www.naspgn.org, 215-333-0808.

Pediatric/Adolescent Gastroesophageal Reflux Association, offers information and support: www.reflux.org, 301-601-9541.