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Motility Disorders that are Commonly Mistaken for Reflux by Susan Agrawal

A surprisingly large number of children with motility disorders experience the same progression of events leading up to diagnosis. As a baby, the child vomits several times a day and spits up constantly. Some children are irritable, do not sleep, or have trouble passing stools. All are taken to the doctor and diagnosed with infant reflux, an incredibly common disorder that affects a large number of babies in their first year of life. Most children are put on Zantac, have their formulas changed, have minimal testing if any, and fail to improve. For parents, the remainder of that first year of life is spent caring for a screaming, vomiting baby, doing lots of laundry, and in general, being very frustrated.

I have two children, a daughter with motility problems and reflux, and a son with infant reflux alone. While both of them managed to bring up copious amounts of breastmilk after every feed, the differences between the two were striking. Sameer, the straightforward refluxer, spit his breastmilk out passively, a mouthful at a time, and only vomited occasionally. He typically spit up or vomited within 30 minutes of a feeding. Keeping him upright helped enormously. He slept well, ate well, gained weight, and was reasonably happy. Of course not all refluxers do this well, but the majority are like my son.

My daughter Karuna was an entirely different story. She would vomit whole feeds with such force that you could feel her entire digestive tract spasming under your hands. She was known to projectile vomit across the room. She would retch and retch with each vomit. She gagged frequently, screamed incessantly, and did not sleep at all. Even three hours after a feed she could vomit three ounces of breastmilk. It was not uncommon for her to vomit forcefully twenty or more times per day. Before vomiting, she often had prodromal symptoms such as salivation, sweating, retching, or an increased heart rate.

Looking back, it seems obvious to me that her incessant vomiting and screaming was not simple reflux, but rather a motility problem coupled with visceral hyperalgesia (an overly sensitive stomach). But she also had garden-variety reflux on top of her motility issues, and unless you observed her for some length of time, all of her symptoms technically fit into the diagnostic criteria for reflux.

What is a motility disorder? In simple terms, it is any condition that interrupts the rhythmic waves of peristalsis (contractions) within the gastrointestinal tract. Motility disorders can affect any part of the digestive tract, from the esophagus all the way to the anus. In most children, motility disorders are neuropathic (caused by the nerves in the

gut not relaying messages properly) or myopathic (caused by the muscles not working well), though there is some evidence that missing or damaged pacemaker cells in the gut, called Interstitial Cells of Cajal, may also contribute to many motility problems.



An old picture of the author's two children, Karuna (2.5) and Sameer (10 months), both showing evidence of their vomiting and refluxing

Technically, reflux is a motility problem, since it is usually a failure of the lower-esophageal sphincter to contract and relax properly. But when most people use the term “motility disorder,” they are referring to conditions such as achalasia (motility problem of the esophagus), gastroparesis (delayed gastric emptying), rapid gastric emptying (dumping), dysmotility, chronic intestinal pseudo-obstruction, constipation, and similar conditions. Describing these conditions in detail is beyond the scope of this article. Please consult this earlier article [<http://www.articles.complexchild.com/00005.html>] for an overview of specific types of motility disorders.

Many doctors are not trained or even particularly knowledgeable about these disorders, leading to frequent misdiagnosis, often for years. Furthermore, with the exception of the rather unreliable gastric emptying scan, most tests used to diagnose motility problems are not widely available. Manometry testing, or evaluation of the strength and coordination of peristalsis (the rhythmic contractions in the gut), is still only available in a small number of children’s hospitals in the United States. It is often difficult to diagnose a motility problem without seeing a pediatric gastroenterologist who specializes in motility.

The signs and symptoms of both reflux and upper gastrointestinal motility disorders are very similar, with only subtle differences between the two. For example, motility problems of the esophagus, such as esophageal spasms or achalasia, cause choking, regurgitation, pain or “weight” in the chest, and coughing. All of these symptoms can also be symptoms of reflux. Similarly, dysmotility or pseudo-obstruction can cause vomiting, abdominal pain, nausea, and bloating, all of which are also symptoms of reflux. While lower motility problems such as chronic constipation may also mimic reflux, there are usually enough distinct additional symptoms related to bowel habits to diagnose these disorders more readily.

The motility disorder that looks most like reflux and occurs most commonly is delayed gastric emptying. Table 1 below compares the symptoms of the two conditions. As can be seen, the symptoms are remarkably similar. The differences are extremely subtle, such as how and when the child regurgitates, and the location of the abdominal pain.

Table 1: Symptoms of Reflux and Delayed Gastric Emptying

Symptoms of Reflux	Symptoms of Delayed Gastric Emptying
Passive regurgitation (spit-up)	Forceful vomiting, sometimes projectile, and often with prodromal symptoms (sweating, salivation, retching, fast heartrate, etc.)
Occasional vomiting (about 1x a day), often related to gagging	Frequent vomiting (2x a day or more)
Regurgitation during/after feedings	Vomiting at any time, long after feedings
Irritability, especially during/after feedings	Irritability at any time of the day
Nausea unusual	Nausea common
Gagging or choking are rare	Retching and gagging are common
Pain usually in throat or chest	Pain usually in belly or intestines
Food aversion or refusal	Food aversion or refusal
Wet burps or hiccups	Excessive burping
Failure to thrive (uncommon)	Failure to thrive (more common)
Malnutrition/dehydration (unusual)	Malnutrition/dehydration (more common)
Bloating unusual	Bloating common
Respiratory symptoms such as cough, hoarse voice, chronic ear/sinus infections, aspiration, apnea, etc.	Respiratory symptoms such as cough, hoarse voice, chronic ear/sinus infections, aspiration, apnea, etc. common in those who vomit

It is very important to get an appropriate diagnosis since some motility disorders, such as severe gastroparesis and chronic intestinal pseudo-obstruction, can be very serious and require significant nutritional intervention using tube feedings, special formulas, or even parenteral (IV) feedings. Some children whose motility problems cause significant vomiting or diarrhea may become dangerously dehydrated or lose weight quickly and need nutritional intervention. Other children may need an ostomy, such as an ileostomy

or colostomy, to help them to remove waste from their bodies. Children with rapid gastric emptying, also called dumping, may have difficulty regulating their blood sugars and need to be treated appropriately to avoid the serious side effects of low blood sugar. When motility problems of the esophagus interfere with eating or cause choking, thickened feeds or tube feedings may be needed.

In addition, a proper diagnosis allows for children with motility problems to be treated appropriately. Children with gastroparesis may improve by taking pro-motility medications, eating smaller meals, or, in more severe cases, being fed by tube into the small intestine. Diarrhea and low blood sugars that result from rapid gastric emptying may be helped by cornstarch or slow, continuous feeds. In children with spasms of the esophagus or stomach, anti-spasmodic medications may be helpful. Some children may also be eligible for surgical correction of their motility problems, through removal of an affected segment of the bowel, creation of an ostomy to drain intestinal contents, or even intestinal transplant. For some children with gastroparesis or pyloric spasms, botox into the pylorus (the valve between the stomach and intestine), or surgery to loosen the pylorus may be helpful.

If your child has been diagnosed with reflux but you suspect she actually may have a motility problem of the esophagus, stomach, or small intestine, the following criteria may help you decide if your child needs motility testing:

- ☐ Reflux medications such as PPIs (Prevacid, Prilosec, Nexium, etc.) have not improved symptoms
- ☐ Spitting up persists past the age of 12 months
- ☐ Vomiting or retching occurs more than once a day, every day
- ☐ Vomiting is forceful or projectile on a regular basis
- ☐ Vomit contains undigested food from many hours earlier
- ☐ Choking or gagging occurs frequently
- ☐ Constant, frequent, or persistent abdominal pain
- ☐ Bloating occurs daily
- ☐ Diarrhea occurs daily, especially if associated with paleness or sweating
- ☐ Failure to thrive, dehydration, or malnutrition has been diagnosed

Remember, however, that many children have both reflux and a motility disorder, and having a diagnosis of reflux confirmed by an Impedance probe or pH probe does not mean a child only has reflux. She may have both reflux and delayed gastric emptying or another motility disorder.

If you think your child may have a motility disorder, it is very important to take your child to a pediatric gastroenterologist familiar with diagnosing and treating motility problems. For many families dealing with more severe gastrointestinal problems, this may mean traveling quite a distance to see a specialist and receive state-of-the-art diagnostic testing. Testing may include:

- Gastric emptying scan to see how fast the stomach empties
- Manometry testing of the esophagus, duodenum, colon, rectum, or anus to detect if the waves or contractions in that part of the gut may be working appropriately
- Breath test for bacterial overgrowth, which often occurs in gastroparesis or pseudo-obstruction
- Sitzmark study to evaluate transit time through the colon
- Standard GI tests, such as upper and lower endoscopies, Upper GI (barium swallow), Impedance or pH probe, or barium enema

If you suspect that there is something more than “just reflux,” trust your instincts and take your child to a motility specialist. The following list of motility clinics should help you locate a center near your region. Please note that many of these centers are brand new (or not even open yet). Some children with more severe conditions should probably visit one of the more established centers, listed first in the list.

Pediatric Motility Centers:

- Children’s Hospital Boston
<http://www.childrenshospital.org/clinicalservices/Site2002/mainpageS2002P0.html>
- Nationwide (Columbus) Children’s Hospital
<http://www.nationwidechildrens.org/GD/Templates/Pages/Childrens/GI/GILongContent.aspx?page=2244>
- Children’s Hospital of Wisconsin
<http://www.chw.org/display/PPF/DocID/28104/router.asp>
- Cincinnati Children’s Hospital
<http://www.cincinnatichildrens.org/svc/alpha/m/motility/>
- MassGeneral Hospital for Children
<http://www.massgeneral.org/children/specialtiesandservices/pedigimotility/default.aspx>
- Floating Hospital for Children
http://www.floatinghospital.org/OurServices/Gastroenterology_Nutrition/default?Page=1
- University of Kansas <http://www2.kumc.edu/kupedigi/> (currently not seeing patients until a new motility doctor is found)
- Riley Hospital for Children <http://rileychildrenshospital.com/physicians/med-sub-specialties/gi/gi-motility.jsp>
- Brenner Children’s Hospital <http://www.brennerchildrens.org/Services/gastro/>
- Southwestern Medical Center
<http://www.utsouthwestern.edu/utsw/cda/dept107933/files/397024.html>
- Children’s Hospital of Michigan
<http://www.childrensdmc.org/?id=103&sid=2#pmcenter>
- Children’s Hospital of Orange County
http://www.choc.org/services/specialties_detail.cfm?id=12

- UCSF Children's Hospital
<http://www.ucsfchildrenshospital.org/childrens/special/g/72476.html> [only minimal testing available]
- UCLA Mattel Children's Hospital
http://www.uclahealth.org/body.cfm?xyzpdqabc=0&id=453&action=detail&limit_department=22&limit_division=1073
- Methodist Children's Hospital of South Texas
<http://mhschildrens.com/CPM/2007MCHDirectory.pdf> (p. 17)
- Texas Children's Hospital (coming soon)
<http://www.texaschildrens.org/carecenters/GINutrition/Default.aspx>
- Children's Hospital of Philadelphia (new)
http://www.chop.edu/consumer/pat_care_fam_serv/staff_profile_page.jsp?sid=26673&id=86953
- New Orleans Children's Hospital (coming soon)
<http://www.chnola.org/content/GastroenterologyHepatologyAndNutrition.htm>