

A PIECE OF MY MIND

Melissa M. Khorana, RN, MS, ANP
Arc of Greater Cleveland, Cleveland, Ohio.

Alok A. Khorana, MD
Cleveland Clinic, Cleveland, Ohio.

Measuring Quality

In the spring of his 17th year, our child Matthew—born with Down syndrome—started to change. Until then, he had had a very consistent personality—sociable, glad-handing in large groups, obsessed with *Power Rangers* and *Goosebumps*. The oldest of 4 brothers, he enjoyed acting out favorite scenes from movies and television shows and repeatedly cataloging his DVD collection.

Then the change happened. Almost overnight, it seemed, tectonic plates shifted in the subterranean of his personality. He became irritable, withdrawn, angry. We initially attributed this to teenage angst, playing out differently with Down syndrome. But we could no longer be in denial when, at his youngest brother's first birthday party, he snapped, punching his mother in the face. Sadly, that was only the start of such episodes. Every month or so, Matthew would become physically aggressive. The episodes were unpredictable—often occurring at public places or restaurants. Sometimes he would hit one of us, sometimes he would punch walls. Often one of us would have to hold him down until he stopped “being the Hulk.” One episode so terrified his younger brother that he called 911. When the police officers arrived, we had to lie and say that we had things under control.

What makes a good, high-quality doctor? The answer—for patients and families—is intuitively, glaringly obvious: *Who can make my loved one better?*

(We did, but only at the moment and our hearts were bursting with anxiety that Matthew would snap any second while the police officers were there, and they would have to take him away.)

His mood was not the only change. There was an initial period of substantial weight loss. There were days of abdominal pain, nausea, and emesis, mystifyingly intermittent. His pediatrician referred him to a gastroenterologist but an endoscopy was unrevealing. His symptoms morphed into episodes of diarrhea, incontinence, even bright red blood in stool. Terrified by this last development, we sought a second opinion. Repeated endoscopies were also unrevealing. Much of his symptom burden was attributed to anxiety and depression in a young adult with Down syndrome and poor articulation, and he was handed off to a psychologist and a psychiatrist. All told, Matthew was evaluated by 7 clinicians from various specialties. Most of the health care professionals he saw were compassionate and caring. We received lots of empathy—but no diagnosis.

As the years went on, psychiatric medications became the default solution in the absence of a clear diag-

nosis. These led to new adverse effects: a severe blunting of his personality and weight gain. Seven long years later, when we moved to a new city, Matthew was 85 pounds heavier and on hefty doses of clonazepam, venlafaxine, lamotrigine, ziprasidone, and diazepam. He still had poorly controlled outbursts and intermittent gastrointestinal symptoms.

What makes a good, high-quality doctor? The answer—for patients and families—is intuitively, glaringly obvious: *Who can make my loved one better?* Yet the medical establishment and its regulators have managed to make this simple question incredibly complicated. There are currently thousands of performance measures and quality models applicable to clinicians.^{1,2} More than \$15 billion is spent annually by US physician practices simply on reporting performance.¹ In addition to governmental regulators, many for-profit ratings agencies have proliferated online, relying on small surveys of unverified patients. Board certification also does not appear to be associated with better quality of health care delivery.³ The national rankings of health care organizations that employ physicians are assumed to be surrogates for quality, although data supporting this are lacking as well.

When we moved, we naturally prioritized finding a good doctor for Matthew. With our years of experience in health care, we did not for a moment consider using board certification status or any of the 2500 performance metrics to find a new physician. Nor did we trust any of the online commercial survey-based reports. We found one the old-

fashioned way: we asked parents of other people with intellectual disabilities. We did not care that the physician recommended was not employed at the time by either of the 2 nationally ranked health care systems in town.

The physician we met as Matthew's new primary care doctor would take all of 15 minutes to transform his and our family's lives. A quick run-through of his symptoms and his impressively long list of medications was all that was needed for her to offer a diagnosis. “I'm pretty sure he has celiac disease,” she declared. “I don't want to give him a new illness, but if I'm right I think we can make him feel a lot better and get him off some of his medications.” She had recently diagnosed celiac in 3 other patients with Down syndrome with a similarly long list of medications. She ordered laboratory tests to confirm her suspicion. We waited, somewhat skeptical that a new all-explanatory diagnosis would be found.

A few days later, she called us on a Sunday afternoon, unable to keep the excitement out of her voice: Matthew's gliadin antibody results were “sky high.” He went on a gluten-free diet immediately. Within

Corresponding Author: Alok A. Khorana, MD, 10201 Carnegie Ave, CA60, Cleveland, OH 44195 (khorana@ccf.org).

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a few months, he was off clonazepam, lamotrigine, ziprasidone, and diazepam and only remained on lower doses of venlafaxine. As we were able to eliminate his medications, his weight gain started to reverse as well. By the end of a year, he had lost 40 pounds. His gastrointestinal symptoms improved, and his periodic outbursts nearly stopped.

Celiac disease is now recognized to be much more prevalent in people with Down syndrome.⁴ At the time, however, these data were just emerging. What allowed Matthew's doctor to identify the diagnosis that so many others had missed? Certainly, she was compassionate and well-trained, but so were the prior clinicians. She was board certified in internal medicine, without further subspecialty training in developmental disabilities or gastroenterology. But she cared about people with intellectual disabilities—enough to have such individuals be a focus of her practice, and for their families to know of her, and recommend her to us. She cared about her patients enough to read the sparse literature on gastrointestinal and mood disorders in Down syndrome, even though this would never be an expected question in board certification tests.

Today, Matthew remains healthy as he approaches his third decade of life. He has transitioned to living semi-independently in the community, and retains his fascination for *Goosebumps*. When we look back at the 7 years of a missed diagnosis and the burdens it placed on our growing family, it is with a mixture of sadness, anger, frustration, and guilt. We shudder at the thought of how many more years Matthew would have had to suffer with tortuous symptoms and repeated health care visits; how his weight gain from multiple psychiatric medications would have caused additional, unnecessary suffering; and how much his potential—already limited at birth—would have been further stolen if we had not found a truly high-quality physician. We are haunted by the fact that even today—in the age of constant measurement—such outstanding physicians are hidden from families in need as desperate as ours by the meaningless morass of metrics and websites paradoxically designed to *identify* value and quality. The value of Matthew living his best life and of being able to again raise our children without fear of harm—priceless for our family—has not, to the best of our knowledge, been captured by any quality metric.

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