



Treating ADHD with evidence, not opinion

By Lia Novotny | September 7, 2017

What if you went to your primary care physician for a hypertension check and she asked how you thought things were going, rather than taking a blood pressure reading? Or you went in for a diabetes exam and your endocrinologist asked how you were feeling but didn't test your HbA1c levels?

For many pediatric patients with attention deficit hyperactivity disorder (ADHD), this is exactly what happens. Parents and kids are asked subjective questions about "how it's going," feedback from teachers, considered critical to proper care decisions, may be missing or incomplete at the time of the exam, and effects of changes to medication or other prescribed therapies aren't charted over time. With incomplete information in hand, physicians must make treatment decisions.

At Boston Children's Hospital (BCH) in 2010, Eugenia Chan, M.D., and Eric Fleegler, M.D., sought to change that situation by creating an online tool, TriVox Health, to quantify and track their patients' ADHD symptoms and collect assessment data from parents and teachers.

It's a treatment model that has implications far beyond ADHD. Tracking health data and putting the

relevant information in physicians' hands between patient visits results in better management of chronic conditions and more favorable health outcomes.

Data when it's needed

Before TriVox, BCH physicians meeting with ADHD patients had ratings from teachers for just 10 percent of their visits and from parents for 30 percent of visits. Teacher ratings were a particular frustration, often arriving months after the visit had actually happened.

"The whole project originally started because we were so frustrated with getting teacher ratings back," says Chan. "You really can't manage medications without knowing what's going on [with the patient] from the teacher perspective; [school is] where the kids are the whole time the medication is working."

"As we started using it, we realized, wow, there are other things we could gather from parents about how [patients'] lives are going," Chan says.

The stakes are not inconsequential. The CDC estimates that 11 percent of children aged 4 - 17 have ADHD. The total healthcare cost for children with ADHD through

age 19 is double that of the general population. And the condition is associated with an increased risk of psychiatric disorders, substance abuse, and even suicide.

But with effective treatment, these risks go way down, and patients experience significantly improved outcomes. Research shows well-managed treatment is correlated with a reduction in utilization and ER visits as well.

TriVox Health, an independent system whose development was funded both by BCH and with philanthropic gifts, captures assessments from parents, teachers and, once they're old enough, patients themselves related to medications, side effects, and quality of life.

The ratings are based on the Vanderbilt Scale, the most commonly used assessment tool for diagnosing ADHD. Responses are measured on a 4-point scale from 0 to 3 indicating the frequency with which the patient exhibits behaviors such as forgetfulness, distractibility, or anxiety.

Parents and teachers receive reminder emails at regular intervals, prompting them to fill out a new set of ratings, which gives physicians the information they need to make evidence-based treatment decisions between visits (usually 3-6 months) and address problems before they escalate.

Today, TriVox Health is used by more than 6,000 patients, is licensed to private practices, and will soon be used by the Developmental Behavioral Pediatrics Research Network, a network of 12 of the top developmental medicine research institutions across the country.

Heading off crisis conditions

Regularly receiving numerical data lets physicians chart ratings over time, identify when symptoms start to reappear, and head things off before they go in the wrong direction.

"Previously, it was common for teachers to not convey that there was trouble brewing until things had been

going on for a long period of time—and perhaps even gotten to a crisis point," says William Barbaresi, M.D., director of BCH's Developmental Medicine Center.

Worsening behavior and deteriorating classroom performance could go unreported for several months. Armed with TriVox data, Barbaresi says, physicians can now call a parent and say, "You know, it is okay now, but there's a high likelihood that before our next scheduled visit we may need to make a change. Make sure you check in with the teacher and let's get an interim set of ratings."

If the feedback indicates a problem, physicians can adjust medications with a simple phone call, avoiding a potential crisis and saving families the average three to four hours and \$100 - \$300 required for an office visit. And the patient may have avoided a potentially damaging disciplinary incident at school or in public.

Better for all stakeholders

In the exam room, TriVox gives physicians the time to fully focus on their patients. With the data collection and forms out of the way, physicians, patients and parents are free to have deeper conversations about treatment options. Chan says, "You don't spend any time scrambling, having parents fill out forms. You can actually just talk about how things are going."

Universally, the feedback from clinicians is that TriVox has changed the dynamic of their visits for the better.

And TriVox has been instrumental in helping BCH keep parents and teachers connected to the patient's progress. "We've gotten a lot of qualitative feedback from teachers that just feel more part of the care team," says Chan. "They feel like their opinions are being valued. They like the fact that we could take their feedback and do something with medication to make their life a little bit easier in the classroom."

Parents find that filling out the surveys helps them pay closer attention to and better understand warning signs.

What's more, asking parents about quality-of-life issues, including feelings of social isolation or physical exhaustion, can help them realize how their child's ADHD affects the entire family. That in turn paves the way for parents to open up to their child's physician in visits.

Keeping patients in compliance with treatment plans

TriVox is also a crucial tool in keeping often patients compliant with treatment plans. One of the most striking effects has been on the care of adolescents with ADHD, according to Chan. It is very common for previously compliant teenagers to simply refuse to take their medication, convinced they no longer need it, she explains.

Rather than duking it out with teenagers, Chan will often suggest a trial in which the teen goes off his/her medication, with the care team capturing parent and teacher assessments and tracking any changes in TriVox, including responses from the teenagers themselves. Then she meets again with the patient and their parents to look at the graphs together.

More often than not, if the graphs show an increase in distractibility, impulsivity or other key metrics, the teen accepts the outcome, Chan says. "I started off with a huge cohort of 7 to 9 year olds who are now 14 to 16, and I think I've been able to keep everybody

who should be on medication on it. Before, half of them would have gone off."

And parents have come to appreciate the objectivity offered by TriVox. Now they can say to their teens, "This isn't me, this isn't your doctor, this is what the data says," according to Barbaresi. As he tells his patients, "It's no different than if you have high blood pressure. We measure it, and if we need to make a change in your medication, we do."

Broader effects

With potential to help track and manage other chronic conditions, and TriVox is now being used by other specialties, including neurology, psychiatry, immunology cardiology and primary care.

The long-term impact of evidence-based management of ADHD may be the most valuable pay off, though, says Barbaresi.

"If you're more likely to be in school, to not be ill, have better mental health, and be less likely to have a substance use disorder, it's hard to imagine that you're not in a better place by the time you are 25 or 30," Barbaresi says. "With good inter-visit management, we can actually extend the duration of time between visits, decrease costs overall, and improve outcomes."

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