

Patient-first approach leads to new tool for asthma

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SALT LAKE CITY — Jordan Gaddis listens to her son more carefully than most.



On the playground, as 3-year-old Graham scrambles around the swing or the slide, she listens for shortness of breath. At night, when he's sleeping, Gaddis strains to hear his coughs. And in the mornings, when she drops Graham off with his nanny and says goodbye, Gaddis listens for the asthmatic wheeze that indicates, maybe, that something is wrong. "My ear is trained to listen to what his breathing sounds like," she said.

It's a scenario that any parent who has

a child with asthma knows. But now families have a little help predicting the next time an asthma attack might hit. It's due to a tracking tool developed by University of Utah physician and researcher Dr. Flory Nkoy.

The tool is part of a new trend in medicine focusing on patient-centered care.

In patient-centered research, "parents or patients become the experts," Nkoy said.

His study is funded by a \$1.9 million grant from the Patient-Centered Outcomes Research Institute, an organization created through President Barack Obama's health care law to support medical research driven by patients.

In the institute's philosophy, patients are involved in every step of the research process. That includes everything from sitting on grant review boards to shaping the research questions that will be asked.

More often than not, patients are also the ones tracking their symptoms and reporting the data back to doctors themselves.

With the eAsthma Tracker, parents told Nkoy that they'd like an electronic tool to track their children's symptoms every week that would send the data directly to their providers.

"They live with the program, they live with the disease," Nkoy said. "They know all the struggles, all the problems, and also — sometimes — help address it better."

For Gaddis, a new mom with a sick baby, the first year was a scary one.

Graham contracted RSV twice before he was 6 months old. For the first year of his life, he was "tethered to his oxygen" and Gaddis was getting up every night to check his breathing.

When doctors finally sent Graham home with an "asthma action plan," Gaddis felt scared and unprepared.

"They're like, 'OK, we think he has this — go home,'" she said. "And you just feel kind of set free in the world and you don't know that much about it."

A year and a half ago, Gaddis joined the eAsthma trial and began recording Graham's breathing patterns, medicine use, sleeping habits and more on the app.

Each week, the tool crunches the data and determine's Graham's risk of an asthma attack as green, yellow or red. The program sends the data directly to the patient's doctor.

Once, Graham's pediatrician saw his risk level rising and called Gaddis directly. They agreed that Graham should start prednisone, and Graham's asthma risk soon returned to safe levels, his mother said.

"It just makes me feel like there's something that I can do to help control a little bit better," she said. "I'm sort of a team with the provider."

Since Gaddis started using the tracker regularly about a year ago, Graham has been stable.

"The current model without the asthma tracker is waiting for a patient to have an asthma attack," Nkoy said. "Let's try to prevent the problem early."

Earlier studies have shown that regular use of the asthma tracker slashed emergency department visits by two-thirds, according to Nkoy.

This time, in addition to reporting their child's symptoms, parents are also recording missed school days, work interruptions and hospital visits due to asthma.

Those were ideas that patients themselves came up with at a Patient-Centered Outcomes Research Institute retreat to discuss the design of the study, Nkoy said.

Dr. Joseph Johnson, a pediatrician who uses the asthma tracker tool with 25 of his patients, said the tool helps patients figure out their asthma triggers and helps him tailor medication for the individual.

"When they come in for their visits, rather than trying to remember what happened two months ago, we have the record that shows your control was good here or it wasn't very good here," Johnson said.

Gaddis, for example, combines the tracker with air quality and weather data. She now knows, with striking precision, how Graham's asthma risk changes in relation to air pollution or cold temperatures.

That's allowed Graham's pediatrician to make small adjustments to his medication when needed.

In addition to Nkoy, several Utah researchers have research institute grants for other projects that aim to enhance diabetes care for Hispanic patients, educate people on how to self-screen for melanoma and improve how patients prepare for and recover from surgery.

The data, perhaps, isn't as clean as if you collected it in a lab experiment with mice, said Dr. Sarah Woolsey, a family physician who is one of the institute's biggest local champions.

But Woolsey said patient-centered data can be much more meaningful.

Patients often care about different things than researchers, Woolsey explained. After a surgical procedure, for example, doctors are obsessed with measuring how fast they can get you back home.

"But for you, what's important when you go home is, 'Can you walk your dog?'" Woolsey said. "For a patient, it's what the quality of their life is when they go home."

How do researchers measure those kinds of outcomes — the ones that really matter to patients?

On March 15, Woolsey is organizing a conference in contract with Patient-Centered Outcomes Research Institute at the University of Utah. Doctors, researchers and community members are invited to talk about their experiences managing their health issues.

Anybody who wants to make the medical community aware about a problem or experience is welcome, Woolsey said.

It's about putting patients "in the driver's seat or in the passenger's seat so they're along for the ride," Woolsey said. "They're co-piloting this."

Woolsey, who serves mostly low-income and uninsured patients at Community Health Centers, learned early on that putting the patient first can lead to better care.

One of her patients, a woman, struggled to control her diabetes. Woolsey realized that the patient was distracted by her teenage son's problems in school. It wasn't until Woolsey and a colleague found a therapist for the patient's son that the woman started to take care of her own health, she said.

"For me, prescribing a counselor for her son was the avenue to treating her diabetes," Woolsey said.

The Patient-Centered Outcomes Research Institute philosophy, according to Woolsey, is simple: Listen.

"Let's improve care," Woolsey said. "But let's improve the care that is important to patients."

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