



J. ADAM NOAH

An experiment at Yale University in New Haven, Connecticut, looking at the impact of social-cognitive processing on stuttering.

THE CONFERENCE CHALLENGES FOR SCIENTISTS WHO STUTTER

Presenting and networking at events can be daunting for researchers with speech difficulties. Here's how colleagues can support them. **By Emily Sohn**

Stuttering affects more than 70 million people around the world. At some point in life, 5–8% of people experience the condition, which is also known as childhood-onset fluency disorder (COFD).

By adulthood, the prevalence is about 1%. Some people naturally recover; others benefit from therapy. Although stuttering (or stammering, as the condition is often called in the

United Kingdom) is the most common condition that affects speech fluency, it is far from the only cause of speech disability. Speech can also be affected by cerebral palsy, hearing loss, strokes and other issues. About 10% of people have a speech disorder.

For scientists, conditions such as stuttering can cause enough stress and social anxiety to impede academic achievement and career success, says Shahriar SheikhBahaei, chief of

the Neuron-Glia Signaling and Circuits Unit at the US National Institutes of Health (NIH) in Bethesda, Maryland.

Making stutterers more visible is a key strategy for boosting the opportunities of scientists who have the condition, argued SheikhBahaei and Gerald Maguire at the University of California, Riverside, in a 2020 paper (S. SheikhBahaei & G. A. Maguire *Int. J. Clin. Pract.* **74**, e13678; 2020).

“As a scientist and a clinician who stutter, we believe if we want to confront this long-ignored condition, we should start in our scientific and medical communities,” they wrote. “We urge scientists who stutter and clinicians who stutter in every career stage ... to give more seminars and conference talks and serve as a role model to show others who are experiencing the same disorder so that becoming a scientist or a physician should not be impeded.”

Nature spoke to SheikhBahaei and two other researchers with speech disabilities about their experiences at conferences, and how colleagues can support them. One requested anonymity to prevent disclosure from interfering with future career opportunities.

ERIC S. JACKSON BE PRESENT AND LISTEN

I've been stuttering since I was about three, and I had a lot of speech therapy that just wasn't good. After college, I went into finance. Then, in my twenties, I had this amazing experience at a 3-week intensive stuttering therapy programme at the American Institute for Stuttering (AIS) in New York City. There were components dedicated to working on cognitive-emotional aspects in addition to speech, motor and behavioural aspects. The therapy I received as a kid mostly focused on the latter. The former allowed me to accept myself as a person who stutters. Most helpful was meeting a whole bunch of other stutters. Learning to talk openly about stuttering was something I started doing at the AIS.

I became a speech pathologist [speech and language therapist] with the goal of working with people who stutter. After receiving my clinical degree, I worked for two years as a preschool-based pathologist. I worked on language-based learning disability, articulation disorders, stuttering, apraxia, autism and others. But I realized that researchers and clinicians didn't know anything about stuttering. It's one of the disorders that we probably know the least about in the field. That prompted me to go and get my PhD in 2011. I study the context-based intermittency with which stuttering occurs and the factors that drive variability, including social interaction and anticipation.

As a scientist, my experience has been pretty positive for the most part. I have really good colleagues and collaborators, with whom my stuttering never feels like a problem. One thing that has been challenging is dealing with the pathologizing that goes on in science. As an example, scientists refer to control groups in studies as healthy controls, which implies the stuttering group is not healthy. I don't think people are intentionally

trying to cause harm, but that doesn't mean that it's not offensive.

It would be super helpful if there was some way to request extra presentation time when people are submitting abstracts to conferences. It would certainly reduce the feelings of time pressure during talks for people who stutter, which would in turn positively affect the talks. My advice to people who feel as if they would benefit from extra time would be to take it if it is offered. I think some people might think they could be inconveniencing others. Normalizing it would go some way to helping people to be aware at conferences.

For me, I have an easier time speaking in front of groups, as opposed to one-on-one, because of the nature of the back and forth. It wasn't always like that, and I was petrified to speak in public. I have been told on numerous occasions by well-intentioned colleagues that they're impressed if I don't stutter a lot during a talk. It implies that the stuttering is the primary focus rather than the content of the talk, and that fluency is good and stuttering is bad, which as professionals in the field isn't a message that we want to be sending.

The kind of chit-chat that happens at a conference is so important. But when people are in a rush to go somewhere else, it can make it really challenging for a person who stutters to engage and get anything out of those interactions. What makes it tricky with stuttering is that, especially if there are other people around who are also talking, if you block [get stuck trying to get a word out] – especially if it's a silent block – then someone else might just jump in. Then, if you finish what you were saying, it could appear as if you were interrupting. When I first started going to conferences, I found chatting much harder. What has helped me is to be really intentional. I just kind of forced myself to insert myself in situations at the risk of being almost annoying. But that was what I had to do in order to take part in these interactions.

If you're a person who stutters, one of the most common reactions from people is this thing we call 'the look'. It's the moment when you stutter and the person you're talking to isn't sure what's happening. The eyes sort of squint, and some people will lean in a little more and do all of these things that maybe they think are helping, but they are definitely not helping. It makes it much harder for the stutterer because it can be perceived as the person thinking you're not smart. The right thing to do in one of those situations is just to wait for the person to say what they want to say. And honestly, this is a good communication skill for anybody to have, regardless of whether the person stutters or not. Just be present and listen.

Eric S. Jackson is director of the stuttering and variability (savvy) lab at New York University.

ANONYMOUS BE PATIENT

My brain sometimes decides it doesn't really like language and takes a break. Sometimes it is just for a few seconds. Sometimes it is half a day or more. Sometimes I can't find words. Other days, I'm not sure what my own name sounds like. It's called transient aphasia – the primary symptom of an electrical neurological disorder. It's completely unpredictable. If I get overly tired or stressed, it happens more frequently.

I was already in graduate school when my body decided to start sending me off into verbal Neverland on a regular basis. Six years and two neurosurgeries later, I'm an academic scientist. But when every job and tenure application requires a seminar, and nearly every university-tenured research position compels commitment towards entirely lecture-based education, speech dysfunction can be a bit inconvenient.

I argue that the bloated value and prestige that the academy puts on 11 unbroken hours of PowerPoint and 15-minute flash talks at each conference is a disservice to our community. Multiplicity and diversity in our methods of communication at the upper levels of science and education can be effective for all of us.

Conferences are inherently loud, stressful, chaotic places. Conference venues that amplify these characteristics – by crowding expo halls, making people have to shout their message to each other or generally devaluing anything other than the keynote speech – can feel disheartening.

One of the most hilariously mortifying experiences was when I lost my voice in the second minute of a 15-minute talk. I spent 13 horrible minutes playing guess-the-phoneme and charades with the audience, while learning about my tolerance for embarrassment.

Even more trying were all the times that my speech disability forced a last-minute decision to hand over my whole presentation to a professor to give it on my behalf. When I tried to answer follow-up questions from my seat in the audience, I didn't have any of the resources I would have had to offset my language dysfunction, such as prepared slides, whiteboards or basic audience rapport.

There have been a bunch of awesome experiences, especially in big, international conferences where you can meet some very interesting scientists. There's a lot of social anxiety associated with aphasia. The best conferences are the ones where I find a group of folks I connect with and can share the chaotic experience with. I remember one where I went on one of the organizer-arranged day hikes. We talked about stats and cats for hours.

Conferences that value more than just talks are pretty cool. By this I mean ones that give

travel support to poster presenters, not just those who give talks. These conferences build decent poster halls, and they don't encourage meals during poster sessions. These policies indicate to participants that the organizers have considered and value the various ways that people interact and communicate their science, and that they encourage researchers of all career stages and abilities to attend, meet and learn.

The accommodations that would benefit me and perhaps a lot of folks with speech disabilities would probably benefit a lot of the wider scientific public as well, like providing designated quieter spaces (with seating and tables) where people can step aside to have conversations, or giving speakers the contact information for moderators before the conference. I would prefer to send a quick e-mail to a moderator a week before a conference to let them know that one of their speakers might lose their voice during their session, and to tell them how to react and help while the speaker initiates a back-up plan. It would be better than tracking someone down minutes before my presentation, or worse, losing my voice and having to explain what is happening using semaphore in front of 50 other scientists. At a conference, a moderator is an asset, but if they don't know, they can't work with you.

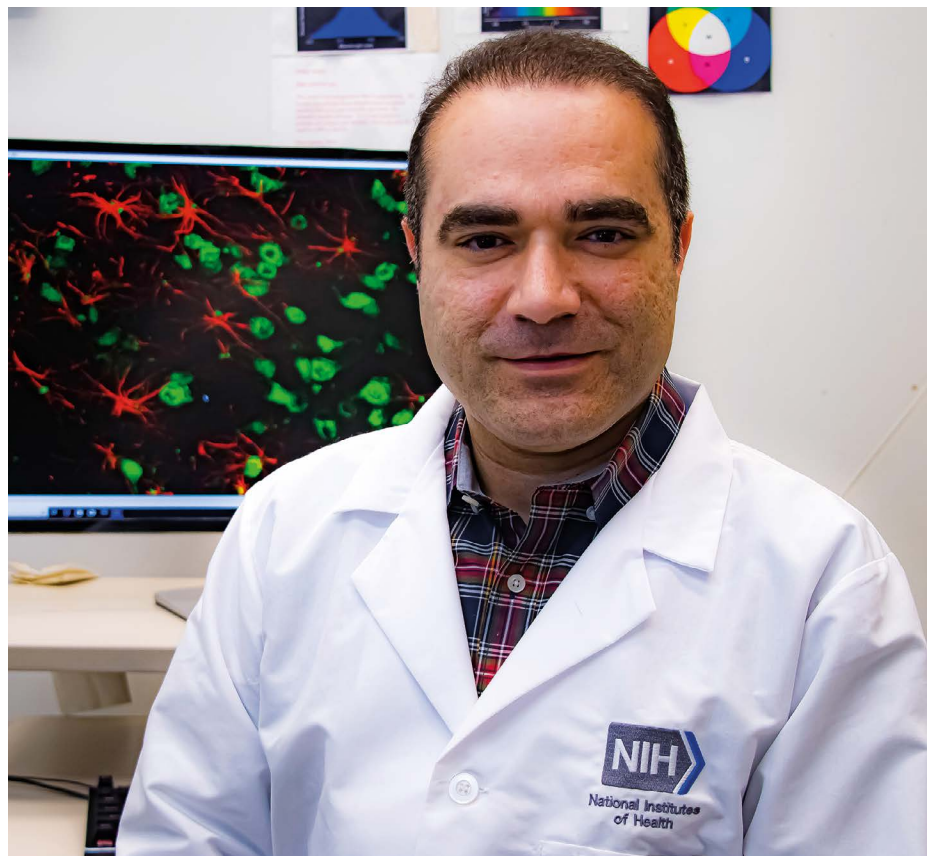
If I had to give myself advice, it would be: 'be patient with yourself; be patient with others'. Not everyone has seen all forms of speech before. Not everyone knows how to react, and their reaction isn't a reflection on you. But that's a tall order when there's a room of people who you desperately want to impress waiting to hear what you've been doing for the past year. I just try to come to conferences with a small arsenal of preparations.

I ask myself, what am I going to do when things inevitably get weird? Do I have a business card for the moment when I need to step away but want to reconnect with someone later? PowerPoint slides pre-recorded just in case? That one phrase in my head to make me smile instead of cringe? I try to prepare these beforehand, not just the data and figures. I'm still figuring this out, but I'm learning to connect with my scientific community as myself, exactly as I sound.

Anonymous is a postdoctoral biologist on the US West Coast.

SHAHRIAR SHEIKHBAHAEI INCLUDE US MORE

The first few years of my life were during the war between Iran and Iraq, and I believe that the trauma of the war contributed to the development of my stuttering. I also have a family history of stuttering, and we know that genetics is a main component for this disorder.



Shahriar SheikhBahaei became interested in neuroscience because of his stuttering.

I got attracted to neuroscience at a young age because of the stuttering, and I had a naive idea to find a cure. In medical school in Iran, I realized that I needed a broader experience to have the impact that I really wanted, so I emigrated to the United States.

Not being able to speak fluently is a struggle. You know what you want to say, and yet you can't say it. As a kid, I was perceived as slow, academically delayed and lazy by some of my teachers. English is not my first language, and when I emigrated, I remember I lost points in my exams because I didn't know the meaning of common words like celery. Bilingual people stutter more in the language that is not their first language, and that is true about me.

When I started my studies in the United States in 2006, I wasn't comfortable giving a talk at conferences. I presented only posters. I was fortunate to have great mentors during my PhD in the University College London and US National Institute of Neurological Disorders and Stroke joint doctoral programme in neuroscience. I learnt a lot from clinical scientist Gerald Maguire, then a clinical scientist at the University of California, Riverside, who also stutters and gave regular presentations. Also, in 2016, my PhD supervisor nominated me to give a talk about my studies at the NIH, and they selected me as one of the few speakers. After that, he spent a lot of days with me over the weekends. We slowly prepared my talk together, and he slowly increased the audience size for me.

When the talk came, the audience was fantastic. They asked questions. This was my main fear: what if people think asking question would make me, as a speaker who stutters, uncomfortable? I gave another talk abroad and I won an award for oral presentation. Those early experiences during my PhD shaped my interest to be involved in my community. I found my voice.

When I give a talk, I usually stutter more at the beginning. As I get to know the audience, I become more fluent. People who stutter can be effective communicators. It might take a little longer for us to give the message, so I think being more flexible with the timing would help.

Another thing that might help would be for conference organizers to invite more people who stutter to make presentations. I strongly encourage people who stutter to volunteer to give talks: these presentations might encourage other people who stutter to pursue science, so we can learn more about this disorder. It will decrease the stigma and make it easier for us and the next generation.

Shahriar SheikhBahaei is an independent research scholar and director of the Neuron-Glia Signaling and Circuits Unit at the National Institute of Neurological Disorders and Stroke, NIH, Bethesda, Maryland.

Interviews by Emily Sohn.

These interviews have been edited for length and clarity.

Correction

This Careers feature erroneously referred to a source's personal experience. It also inaccurately stated that Shahriar Sheikhabaei's PhD was done at the US National Institute of Mental Health and that Gerald Maguire nominated him to give the talk at the NIH.