



ILLUSTRATION BY SAM FALCONER

The psychological toll of food allergies

Bullying, anxiety and depression can have a huge impact on the lives of people with allergies and their families. **By Roxanne Khamsi**

Just before Thanksgiving in November 2005, paediatrician Ruchi Gupta gathered some parents of children with food allergies in an office building. She aimed to collect data on their knowledge and beliefs about allergies, but the conversation quickly turned emotional.

One parent described how her family wouldn't be joining the big Thanksgiving gathering because of her son's allergy. "She started crying and she was very emotional about it, and said they were just going to do Thanksgiving on their own," recalls Gupta, director of the

Center for Food Allergy and Asthma Research at Northwestern and Lurie Children's Hospital in Chicago, Illinois. "The whole focus came out." The meeting was planned to last an hour, but people stayed well into a third. Other parents opened up about their distress. "They started talking about their experiences in every realm of life: people who didn't believe them, even in their own families. A lot of times the grandparents would say, 'Oh, you're just over-protective. We didn't have this in my day!'"

Gupta decided that this was no coincidence;

people with food allergies, and their families, needed more mental-health support. She conducted six more focus groups over the next six months, before publishing a paper detailing some of the anxiety felt by parents of children with food allergies¹. It described how parents experience "emotions of fear, guilt, and even paranoia". In the years since, she has continued to research the effects of food allergies on families, and last year published an analysis of available mental-health resources².

Gupta is part of a small but growing number of doctors and counsellors who are trying to

understand the scale of this problem, and how to support patients and their relatives who experience issues such as bullying, depression and anxiety. The need for such support has become more pressing partly because food allergies have become more common. Among infants under the age of one, for example, the incidence of peanut allergies in the United States rose from an estimated 1.7% in 2001 to 5.2% in 2017. And a study from the Blue Cross Blue Shield Association, a federation of US health-insurance companies, found that urgent hospital visits for food allergies increased by 150% from 2010 to 2016.

“A lot of these kids are getting diagnosed as babies, so they haven’t even experienced anaphylaxis or they don’t remember it, so it’s really the parents who are anxious,” says Jea-Hyoun Kim, a psychiatrist at the Valley Homeless Healthcare Program in San Jose, California. She explains, however, that parents’ anxiety can be passed on to their kids. “If your mom is constantly saying things like ‘Don’t touch that’ and ‘Don’t eat that’, you’re going to start internalizing it, and you’re going to become anxious as well.”

Kim and her husband Charles Feng, an allergist at the Palo Alto Medical Foundation in Mountain View, California, decided to delve deeper into the impact that food allergies have on mental health after Kim did a presentation on it in the last year of her residency. Together, they authored a review on the subject³, which noted that “food allergies can have a profound effect on a family’s life, trickling into aspects of day-to-day living both large and small”. Little did they know that their own family would be directly affected by food allergy. Their son, who was born last December, was recently diagnosed with a reaction to soya beans.

Feng thinks that more attention needs to be given to mental health. “The psychological repercussions of food allergy – just thinking about and worrying about it and getting anxious over it – is sometimes more serious than the food allergy itself,” he says. Feng recalls treating a 12-year-old who was so anxious about her peanut allergy that she would sleep holding an EpiPen (an auto-injector for adrenaline, also known as epinephrine). One thing that proved to be a game-changer for her was receiving oral immunotherapy, a process in which small exposures to the allergen under the supervision of a doctor help to train the body to be more tolerant of the food. “Her life completely changed,” Feng says. “She’s no longer sleeping with an EpiPen and her grades are better.”

But oral immunotherapy doesn’t work for everyone, and for some, avoiding dangerous foods is a constant worry. “It’s kind of like living in a minefield,” says Scott Sicherer, director



Food banks do not always ring-fence goods that are suitable for people with allergy.

of the Jaffe Food Allergy Institute at the Icahn School of Medicine at Mount Sinai in New York City. “Every social activity, every birthday party – everywhere you go, there’s food and that means worrying, ‘Is this food safe?’” Kim and Feng note in their review that children with food allergies do not experience anxiety disorders more often than others their age. But some show increased anxiety when coping with the stress of avoiding allergens and are fearful when their parents are not around.

“One in three children with food allergies reported being bullied as a result of their food allergy.”

The anxiety of living with food allergy has been compounded by the COVID-19 pandemic, says Lisa Gable, chief executive of the advocacy organization Food Allergy Research and Education (FARE) in McLean, Virginia. Gable notes that as a result of the economic downturn, many people are relying on food banks, which do not always set aside foods that are appropriate for individuals with food allergies. Online food stores also sometimes substitute unavailable products with ones that contain unsuitable ingredients. This, Gable says, has made the pandemic “particularly stressful” for people with food allergies.

Hidden bullying

In addition to feeling anxiety, people with food allergies can face bullying. “One in three children with food allergies reported being

bullied as a result of their food allergy,” says Gable. “It’s a pretty high rate.” And research suggests that parents are not always aware. A 2013 study from Sicherer and his colleagues found that around half of parents of children with a food allergy did not know that their child experienced bullying in school⁴. “It can be a shock to the parents,” he says.

Bullying can also affect adults, says Gianine Rosenblum, a clinical psychologist in Lawrenceville, New Jersey, who served on FARE’s psychosocial issues task force. “Bullying is absolutely a real thing in food allergy, and it ranges from microaggressions – eyerolls and a derisive tone of voice – all the way up to literally life-threatening [acts like] sneaking food into someone’s lunch or splashing them with milk,” Rosenblum says. Teenagers and adults also have to navigate uncomfortable situations that children don’t, she adds. “They talk about dating anxiety – when and how and where do you introduce the fact that I can’t kiss you if you eat this,” she says. “It’s really painful and burdensome.”

FARE and other groups have taken issue with how films have portrayed such bullying, sometimes using an allergic reaction as a punchline. In the 2018 children’s film *Peter Rabbit*, for example, a rabbit fires a blackberry down the throat of a human with a severe allergy to the fruit, causing him to go into anaphylactic shock. “That really bothered the food-allergy families because that empowered kids to think it was funny to do something like that,” Gable says. “We need help from Hollywood in making sure that they understand it’s not a laughing matter. It’s a life or death matter.” After patient advocates raised objections, Sony Pictures, the studio behind the film, issued an apology.



The film *Peter Rabbit* as been criticized for using an allergic reaction as a punchline.

Some real-life stories have heartbreaking endings. In 2017, 13-year-old Karanbir Cheema, who was allergic to milk and several other foods, died after two classmates exposed him to cheese at his west London school. He went into shock, and use of an EpiPen that turned out to be a year out of date did not reverse his reaction. He died 10 days later in hospital.

That same year, a 14-year-old girl in Pennsylvania rubbed pineapple on her hand and then high-fived a peer who she knew was allergic to the fruit. The child was treated in the hospital and survived, but police charged the 14-year-old with aggravated assault and criminal conspiracy.

However, allergists are cautious about over-emphasizing these events. “While it highlights the seriousness of food allergies, it can make parents even more anxious,” Sicherer says. “It could lead to over-reactions like wanting to keep their child home from school or camp. When I talk to parents who ask about these stories, I contextualize it so that it doesn’t cause over-reactions that limit lives further.”

Sicherer and his collaborators conducted a survey of 98 allergists to assess how often they engaged with their patients on the subject of bullying⁵. Only around 8% always asked their patients about the topic, and around 20% said they never asked.

One of the surprising things that Sicherer and other researchers have uncovered is that teachers can inadvertently belittle children, for example by telling a classroom of students that they have to watch a movie in lieu of enjoying birthday cake and treats because one of the class members has a food allergy. “Even adults who weren’t really thinking that they were causing stress were causing stress for the child,” Sicherer says.

Various efforts are aiming to address issues such as bullying and anxiety. FARE, for

example, has made a public-service announcement called ‘It’s Not a Joke’ to raise awareness. The organization also has an educational programme called Be a PAL to teach children how they can support friends with food allergies.

Physicians agree that these approaches are important. “We have to educate these kids,” says Gupta, who has developed videos with others at Northwestern to educate schoolchildren about food allergies. When she visited schools to test the videos, she found that children with food allergies tended to be shy to come forward. “They didn’t want to identify themselves,” she says. “Then we’d show this video and all of a sudden, this kid with food allergy would come alive and say, ‘Oh, yeah, yeah that happened to me,’ and, ‘Oh I know how to use epinephrine.’ It was really empowering for the kid with food allergy, but also for the peers because they wanted to understand it more.”

Sicherer is helping with his institution’s EMPOWER (Enhancing, Managing and Promoting Well-being and Resiliency) initiative, which aims to recognize behavioural and emotional challenges related to living with food allergies. “There’s been a stigma about mental health,” Sicherer says, “but one of the things I emphasize for my patients is that the majority of people with food allergy recognize that they can use some help. It’s normal.”

Making a connection

But getting that help is not always easy, says Rosenblum. “It can be hard to find mental-health professionals that understand food allergy,” she explains. One of EMPOWER’s goals is to teach such individuals how to support people with food allergies and to show clinicians how to spot issues such as anxiety.

Tamara Hubbard, a counsellor in Long Grove, Illinois, has helped to connect people

with sympathetic professionals through the Food Allergy Counselor website. Launched in 2018, the site includes a directory of allergy-aware counsellors. Hubbard has a child with food allergy, and she initially thought the work might hit too close to home, but is now glad to have embraced the project. “It’s like I knew I had to explore it or I’d regret it,” she says.

Getting support can be difficult in other countries, too. “There are very few mental-health resources specifically for people with food allergy here in the UK,” says Rebecca Knibb, a psychologist at Aston University in Birmingham. “People mainly use the resources that are on the Anaphylaxis Campaign and the Allergy UK websites.”

Special summer camps might provide a venue for children with food allergies to gain confidence. Knibb followed 24 children aged 11 and 12 who attended a week-long camp that involved orienteering, climbing, raft building, archery and two sessions on allergy management⁶. She found some evidence of improvement on questionnaires measuring social quality of life, and for some children this seemed to persist for months afterwards. However, the study had limitations, including the lack of a control group, so it is not possible to draw general conclusions.

Another option is to attend support groups. FARE maintains a directory of in-person and virtual support groups, and numerous Facebook groups offer a sense of community for people with restricted diets.

Rosenblum, who has a 19-year-old daughter with peanut and tree-nut allergies, says people with food allergies can sometimes benefit from finding a safe outlet for risk taking, such as engaging in sport or public speaking. “What do you do to get your adrenaline going safely?” she asks her patients. Rosenblum thinks that such outlets can offset some of the strain of living with the stress of food allergy. Her own daughter fell in love with circus arts. “She does aerial trapeze and stilts,” she says. “With food allergy you have to create a bubble, but you don’t want that to extend to kids not feeling that it’s OK to ever take a risk. You have to take a risk to grow.”

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