DEEP DIVE

Unseen agony: Dismantling autism's house of pain

BY **SARAH DEWEERDT**

21 MAY 2015

Illustration by Nick Ogonosky

As a child, Noah hated when his mother vacuumed the house. "She would put the vacuum on the wood floor, not the carpet," he remembers. "And that's really loud, so it would really freak me out."

Noah, who asked that his last name be withheld, was diagnosed with a mild form of autism called **Asperger syndrome** as a college student (Asperger syndrome has since been **subsumed into the larger category** of autism spectrum disorder).

Now in his early 30s, he counsels other men with autism and teaches psychology in Boston. But as a child, he didn't realize his sensory world was different from other people's experiences.

"At first I would scream and yell for her to stop, but she had no concept that what she was doing was irritating," Noah says. "And I had no idea that what I was feeling was not what everyone else felt."

Noah eventually came to accept that the noise of the vacuum, like many other sensory experiences, was something he just had to suffer through. As a result, "I was very numbed off," he says. "I could handle really intense cold or even pain and not do anything, not feel too much."

Noah's experience illustrates the paradox of pain in autism. On the one hand, some people with autism can tolerate extreme heat, cold or pressure and seem relatively insensitive to pain. On the other hand, they may experience intense pain from idiosyncratic sources but struggle to communicate it.

"It's interesting to me that those two ideas can be held in mind at the same time by the field," says **Matthew Lerner**, assistant professor of psychology, psychiatry and pediatrics at Stony Brook University in New York.

A closer look at the literature confirms that although some people with autism are insensitive to pain, others are unusually vulnerable to it. Sensory sensitivities — exaggerated reactions to certain sounds, lights or other stimuli — affect up to 70 percent of people with autism. Pain may emanate from autism-related health issues such as gastrointestinal problems. And difficulties with sleep, anxiety and perseveration, or the tendency to fixate on a particular thought — all common features in people with autism — may intensify pain.

Recognizing this pain is a serious challenge, however, because people with autism have unusual ways of expressing it. This, too, may feed into a perception that they don't feel pain.

"That's really intensely problematic when it comes to injections or medical interventions for people with autism," says **Clare Allely**, lecturer in psychology at the University of Salford in Manchester, U.K.

One French study found, for example, that fewer than half of children with autism were given a local anesthetic before having blood drawn, even though this practice was routine for typical children[1].

Skin on snow:

The idea of an altered experience of pain in autism dates to the first descriptions of the disorder. Leo Kanner mentioned abnormal sensory processing, such as a girl who had an odd, detached reaction when pricked with a pin, when he **coined the term autism in 1943**. Later case studies describe, for example, a girl with autism who played in the snow with no clothes on, and a boy who cinched his belt so snugly it dug into his skin, and once grabbed a hot frying pan without flinching[2].

These anecdotal reports gave rise to a prevailing view, unquestioned for many years, that people with autism tend to be insensitive to pain. In fact, many clinicians interviewed for this article say they've known people with autism who seem similarly impervious to pain, which may help explain why the notion held sway for so long.

"I had no idea that what I was feeling was not what everyone else felt."

But beyond this scattered evidence, there is a paucity of solid research on the topic.

"I was surprised by how little literature exists on autism and pain," says **David Moore**, senior

lecturer in psychology at Liverpool John Moores University in the U.K., who last year published a review of the field[3].

Until scientists have a clearer grasp of how people with autism feel and show pain, Moore says, doctors may continue to overlook their signs of distress — and perhaps serious medical issues for which pain is an important sign, such as broken bones and infections.

“Just because there are cases where individuals don’t experience pain, to ignore the potential pain and suffering of other children with the same diagnosis is equally dangerous,” he says.

The few rigorous, well-controlled studies in this area hint that the idea that people with autism are insensitive to pain is largely a myth. For example, three experimental studies in which researchers subjected volunteers to a mild electrical shock, pressure, heat or cold suggest that people with autism have normal pain thresholds or may even be more sensitive to pain than others are[4,5,6].

A couple of other studies have tracked children’s reactions to having blood drawn, recording their cries, grimaces and physiological responses such as heart rate[7,8]. Overall, these studies, too, suggest that children with autism experience similar levels of pain as typically developing children do.

If anything, people with autism may experience more pain than others because of other medical problems. For instance, they have trouble sleeping regularly, and a few studies have begun to explore how this might affect their response to pain.

In one online survey published last year, 62 mothers of children with autism reported a strikingly high prevalence of both sleep problems and pain-related behaviors in their children[9]. More than 90 percent of the children slept too much or too little or had nightmares or breathing irregularities while asleep. And more than 90 percent scored above the cutoff for behaviors that signal pain, such as moaning, grimacing or seeking cuddles.

Not surprisingly, children who exhibit more pain-related behaviors in a given week also have more sleep problems. Not sleeping well could also sap a child’s ability to deal with pain and lead to more behavioral issues in general.

Gastrointestinal problems may also distress children with autism. A parent survey last year found that 58 of 225 children had experienced abdominal pain for at least three months[10]. One year later, more than 85 percent of these children still had these problems. And nearly one-quarter of the children who hadn’t had abdominal pain at the beginning of the study developed it by the end.

A thousand needles:

Nick Ogonosky

The gut study also hints at ways the psychological fallout from autism may enhance pain.

Anxiety can contribute to gastrointestinal problems in the general population. Likewise, anxious children with autism are more likely to have stomach pain.

In the general population, too, anxiety amps up the pain a person feels from an injury, and anxiety is especially **common in children with autism**. This anxiety might make people with autism highly attuned to their aches and pains, though there is no direct evidence for this connection.

“Sometimes it’s hard to tell what is causing what if we’re seeing all those symptoms together,” says Micah Mazurek, assistant professor of health psychology at the University of Missouri-Columbia.

Other characteristics of autism might also make people on the spectrum more psychologically vulnerable to pain. Noelle Giesse, a mother in Queens, New York, says that when her 15-year-old son Matthew, who has autism and Crohn’s disease, suffers bouts of abdominal pain, the agony tends to overwhelm him. Perhaps because of an autism-related tendency to perseverate, he’s unable to distract himself from his discomfort by going about his daily activities the way his sister can.

Mazurek and her team discovered that in autism, sensory sensitivity is even more strongly associated with pain than anxiety is. Children reported by their parents to be hypersensitive to sound, smell, tactile and other stimuli tend to have more abdominal pain to begin with, and are more likely to develop new abdominal pain.

“They may be likely to find lots of different stimuli to be painful, including gastrointestinal stimulation,” says Mazurek. The normal bodily sensations of digestion and elimination might be so intense and unpleasant that they avoid going to the bathroom and develop constipation, setting off a vicious cycle.

This sort of hypersensitivity may make what others would consider only mild provocations intensely painful for people with autism. Noah says there are lots of sensations he can’t abide, from the harsh ringing of a telephone to the feeling of his ankle bones touching each other. Making eye contact with another person is similarly unbearable for him.

When he was working at a summer camp for children with autism, Noah says, he once heard one boy respond to another boy's annoying, singsong repetition of "to-MAY-to, to-MAH-to" with: "Stop saying that. It feels like you're pricking me with a thousand needles."

Despite that sharp visual, Noah says this kind of description is only a metaphor: His sensory sensitivities don't feel like the physical reality of a cut or bruise.

"My response will be very similar to someone who's in pain, but it comes from a different place," he says. "It's just that it's an all-encompassing, irritating process that envelops your whole brain."

Silent scream:

Even as all these coalescing factors conspire to enhance pain in people with autism, that pain can be extraordinarily difficult to recognize.

In a 2009 study, researchers found that the hearts of children with autism pounded faster while they had their blood drawn than did those of typical children[8]. But the children with autism made fewer facial expressions, such as grimaces, that indicate pain, perhaps because they have a smaller repertoire of expressive behaviors in general.

"The challenge with autism is that we're dealing with a population that has altered social behavior," Moore says. "And pain behavior is a fundamentally social thing."

Some people with autism may communicate pain in counterintuitive ways. Giesse recalls Matthew's reaction right after getting his tonsils removed. He threw a tantrum, screaming that he wanted to go home — despite his throat presumably being in significant pain.

Later, Matthew told his mother he had screamed precisely because his throat hurt so much. "But he couldn't express that to us; for him, it was just to scream," Giesse says.

Unable to express themselves, some children may turn their frustration outward — or even against themselves.

Nick Ogonosky

“A lot of times, pain may be exhibited as an exacerbation of behavioral problems or increased self-injury or aggression,” especially in people with autism who have limited verbal abilities, says Mazurek.

Little research has been done on this topic, but the very behaviors interpreted as a high tolerance to pain — such as head-banging or hand-biting — might be signs that the individual is in agony.

There is some evidence that, at least in some genetic subtypes of autism, there may be a biological basis to pain tolerance. For example, individuals with Phelan-McDermid syndrome, a genetic abnormality often accompanied by autism, are often impervious to aches. Mouse models of this disorder **share this feature**.

The original 1966 description of Rett syndrome, an autism-linked disorder that affects mainly girls, also alludes to the girls’ ability to withstand great discomfort.

In 2010, the first study to systematically explore pain in Rett syndrome surveyed 646 families in Australia, France and elsewhere, and found that 65 percent of the parents reported that their daughters had a delayed or muted pain response**10**.

Some girls with Rett laughed instead of crying when they were injured, the parents said. “Often they fractured bones and nobody knew,” says study leader **Helen Leonard**, an epidemiologist at the University of Western Australia near Perth.

Fractures are a particular problem in girls with Rett syndrome, who tend to have decreased bone density. Families and doctors who care for girls with syndrome “really have to be on the alert for prevention of fractures,” says Leonard. Her team is developing guidelines for protecting and healing the fragile bones of girls with the disorder.

Rett syndrome is caused by a mutation in **MeCP2**, a gene that governs the expression of many thousands of others. In the past several years, animal studies have shown that MeCP2 helps to orchestrate the perception of pain in the body. Blocking the gene’s action in a rat can suspend the perception of pain after an injury, perhaps explaining the delayed pain responses of girls with the disorder.

MeCP2 has also been implicated in autism, so this mechanism might contribute to altered sensitivity to pain in some individuals with autism as well, Leonard says. But this idea is still speculative.

No longer numb:

For some people with autism, growing up may bring relief from many sources of pain.

But waiting for this relief isn't a practical solution. Instead, parents and doctors need better ways of identifying and measuring pain in people with autism.

Rabbit relief: Matthew Giesse, who has both Crohn's disease and autism, plays with one of his pet rabbits during a relatively pain-free moment.
Courtesy of the Giesse family

To start, researchers say they need to systematically study pain in people with autism so that they can sketch out variations in pain sensitivity and expression across the autism spectrum.

Moore and Allely say they are interested in conducting psychological and imaging studies to help them trace pain through the nervous system in people with autism. They aim to determine, for example, whether nerve endings register painful stimuli differently or the brain interprets pain differently in individuals with autism than in controls.

Other researchers are attempting to disentangle the cause-and-effect relationships between pain, health problems and psychological traits. This work could eventually enable clinicians to ease the pain of people with autism by addressing its root causes, even if those causes aren't purely physical.

Lerner is exploring how people with autism express pain, asking those with good verbal skills to help interpret the pain-related behaviors of others on the spectrum. The goal is to draw on these insights to learn how to decode the behaviors and facial expressions of people with autism. Speaking of his collaboration with those he is trying to help, Lerner quips, "Who better to ask about the difference than the experts?"

In the meantime, those on the spectrum are finding ways of preventing and soothing their own discomfort.

Noah, for example, has learned how to recognize and manage the quirks of his sensory world. He often wears headphones when he goes out in public so that he can control his auditory environment. And he feels much less numb, in general, than he remembers being as a child, a change he attributes to the increased self-understanding that came with his autism diagnosis in early adulthood.

"It took me a long time after I discovered that to be able to open up a little bit more to my senses,

and feel things like a typical person would," he says.

REFERENCES:

1. Rattaz C. *et al. Pain* **154**, 2007-2013 (2013) **PubMed**
2. Allely C.S. *Scientific World Journal* **2013**, 916178 (2013) **PubMed**
3. Moore D.J. *Autism* **19**, 387-399 (2015) **PubMed**
4. Bird G. *et al. Brain* **133**, 1515-1525 (2010) **PubMed**
5. Fan Y.T. *et al. Soc. Cogn. Affect. Neurosci.* **9**, 1203-1213 (2014) **PubMed**
6. Cascio C. *et al. J. Autism Dev. Disord.* **38**, 127-137 (2008) **PubMed**
7. Nader R. *et al. Clin. J. Pain* **20**, 88-97 (2004) **PubMed**
8. Tordjman S. *et al. PLoS One* **4**, e5289 (2009) **PubMed**
9. Tudor M.E. *et al. Autism* **19**, 292-300 (2015) **PubMed**
10. Downs J. *et al. Am. J. Med. Genet. A* **152A**, 1197-1205 (2010) **PubMed**