

Siblings + the Spectrum: The Prevalence of ASD Across Families

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As Autism Awareness Month comes to a close, I wanted to share with you where my personal history with autism began. The first time that I not only encountered a patient diagnosed with autism, but had ever even heard the word, was during my first year as a pediatric resident some 16+ years ago. The patient was a 4-year-old girl, who was admitted for a congenital heart condition, and upon processing her intake and detailing her history, her parents revealed to our team of doctors, interns, and attending physicians her autism diagnosis.

HITTING THE BOOKS

I remember asking myself “what is autism?” and that night I went home and fell into a rabbit hole of research, attempting to devour as much information as I could find about Autism Spectrum Disorder. It was over the course of that week, while spending hours of hands-on time with the patient, that I learned a lot about this diagnosis. I quickly started to notice nuances in her behavior which I would later come to identify as common characteristics of those on the autism spectrum – she struggled with transitions of her care settings (moving from her patient room to x-rays, etc.), she was much more difficult to console when upset, and she didn't sustain eye contact. Again, as a new intern in the early 2000's, I was one of many pediatric doctors who had yet to experience and learn about children on the autism spectrum.

THE QUESTION

Every day during rounds, the care team was focused mainly on her primary diagnosis – her heart condition; however, I was equally focused on her autism diagnosis and wanted to learn as much as I could about the condition so that I could appropriately support the family. While working with her parents, their emotions were often palpable, and I could always see something else that they were concerned about, but not quite ready to share. On the day my patient was being discharged, the family opened up to me with their question: how likely is it for a younger sibling to carry the same diagnosis?

FAMILY PREVALENCE

I learned that their daughter had been conceived by way of a sperm donor, and they had very recently become pregnant again with a second child from the same donor. The question that they wanted to know – and were hesitant to ask – was: what is the likelihood that their unborn baby would carry the same diagnosis? What would that child's future hold? At the time, I didn't have an answer for them, but I promised to do all the research I could and share with them what I found. We stayed in touch after they were discharged, and I checked in from time to time, and learned they had a beautiful baby girl who was not diagnosed with Autism Spectrum Disorder. We now know that the risk of a second child being diagnosed with autism is fourteen times higher when an older sibling is on the spectrum. Studies have also confirmed that parents who have an older child with an autism diagnosis are more likely to have their younger siblings tested as well, possibly resulting in a higher rate of diagnoses, when compared with parents who don't have an older child with autism.

FORWARD MOMENTUM

One of the greatest teachers in life is that of experience, and for me, this experience was eye-opening. Due to ongoing research, we have learned so much about Autism Spectrum Disorder in general, including family prevalence. Today, physicians are better equipped to tackle the tough questions and concerns that many parents have. Thanks to Autism Awareness Month, which takes place every April, the breadth of knowledge and understanding has driven us to dive deeper into the fountain of knowledge surrounding autism.



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