Why Has the Diagnosis of Autism Spectrum Disorder Recently Increased?

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Abstract

This scientific paper covers the history of Autism Spectrum Disorder, details about the disorder, including symptoms and treatment, information about the diagnostic process, and reasons why this diagnosis has increased drastically in the past few years. However, there are a few limitations to the studies and discussions mentioned in this paper, including some of the sample sizes and the nuance of this issue. Since the diagnosis of autism spectrum disorder has only recently and drastically increased, it is essential to note that there is not much research currently published surrounding this topic, including why this may be happening. Thus, the following analysis is based on what can be said about the increase in the diagnosis of autism and can change in future research.

Keywords: autism spectrum disorder; DSM; symptoms; autism; a developmental disorder.

1. Introduction

A History of Autism

There are certain conditions, such as claustrophobia, that scientists can easily link to their correct diagnostic criteria, including symptoms and other tell-tale signs. However, this is not the case with autism. When autism was first coined as a term, scientists used it to describe a form of childhood schizophrenia, which scientists linked to poor parenting. However, as time passed, it became a developmental disorder and is now known as a spectrum condition with many symptoms and other defining criteria. The “Diagnostic and Statistical Manual of Mental Disorders” (DSM), a diagnostic manual used in the United States, has captured the rapidly changing nature of autism spectrum disorder. Psychiatrist and physician Leo Kanner first described autism in 1943, mentioning that children experience “extreme autistic aloneness” and an “anxiously obsessive desire for the standard of sameness.” However, he also highlighted that children with autism were often brilliant, and some had remarkable memory. Because he described this disorder, Kanner saw autism as an emotional disturbance that does not affect mental cognition. Therefore, in 1952, the DSM-II defined autism as a psychiatric condition comprised of a form of childhood schizophrenia that included detachment from reality.

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In the 50s and 60s, autism was known as a condition that was a result of detached mothers. Additionally, a man named Bruno Bettelheim described these emotionally detached mothers as ‘refrigerator mothers,’ which was later disproved in the 60s and 70s due to the growing accumulation of data showing that autism pointed to having biological roots in brain development. Finally, in 1980, the DSM-III defined autism as a separate diagnosis from schizophrenia, a ‘pervasive developmental disorder’.

The DSM-III was the first edition of the manual that defined essential features or symptoms of autism, which included a lack of interest in people, impairments in communication, and out-of-the-ordinary responses to the environment, which all develop in the first 30 months of life. However, in 1987, the DSM-III was revised, which ultimately changed the criteria that defined autism. Firstly, it added a more mild diagnosis on the less extreme end of the spectrum called ‘pervasive developmental disorder-not otherwise specified (PDD-NOS),’ which eliminated the requirement for symptoms to arise before the first 30 months of life. This change broadened the concept of autism by subtly defining it as a spectrum disorder that takes many different forms.

However, it was not until the DSM-IV, which was released in 1994 and revised in 2000, that actually defined autism as a spectrum disorder. This manual version comprised five different autism spectrum disorder conditions, all with different criteria. Other than the regular definition of autism and PDD-NOS, this version of the manual added ‘Asperger’s disorder’ (on the mild end of the spectrum), ‘childhood disintegrative disorder (CDD),’ which included developmental ‘reversals and regressions,’ and Rett syndrome, which affects movement and communication. Eventually, this led scientists to believe that autism is directly related to genetics and that each category of such would be connected to its own criteria and treatment options.

During the 1990s, researchers and scientists established their ultimate goal; identifying the genes that are involved in and responsible for the development of autism. Many studies attempted to find a list of what they decided to call ‘autism genes,’ and while they found hundreds, they could not link any of them directly to autism. It became clear that finding genetic ‘underpinnings’ and their ‘corresponding treatments’ for each of the five conditions would not be realistic, let alone possible. Similarly, during this time, people were worried about the fact that clinicians in different states and among different clinics were diagnosing autism inconsistently. In the 2000s, the diagnosis of autism spiked drastically, but this suggested that clinicians were swayed into doing such by external forces. So, to address this concern, the DSM-5 helped to introduce the term ‘autism spectrum disorder,’’ which can be defined with two separate features: “persistent impairment in reciprocal social communication and social interaction” and “restricted, repetitive patterns of behavior,” which can be detected in early childhood. However, this immediately started the controversy, even before it was released in 2013. People with autism and their caregivers were concerned about this manual’s effect on their lives because as their diagnosis was removed from the manual, they thought they would lose services or insurance coverage [1].

2. Materials and Methods

In this paper, a number of studies have been collected and analyzed; specifically those regarding the history of autism, the current autism criteria, symptoms and treatment related to the disorder, the diagnostic process, and the possible answer as to why the prevalence of autism has recently increased. As such, this paper aims to gather
an accumulation of facts, data, and information from current or outdated studies, compare them, and conclude on the potential explanations surrounding the current status of this developmental disorder.

3. Result

Current Autism Criteria

For the future of autism research and treatment, clinicians want to continue viewing autism as a spectrum of conditions, an important scale that defines autism in its most accurate way [1]. The most recent version of the DSM-5, called ‘DSM-5-TR,’ did not make significantly different changes from the DSM-5, but the revisions are definitely worth mentioning. Firstly, the DSM-5 states that the diagnosis of autism requires “persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following”: ‘deficits in social-emotional reciprocity, in nonverbal communicative behaviors used for social interactions, and in developing, maintaining and understanding relationships. The first revision, as seen in the DSM-5-TR, adds only two words to the exact description above: “as manifested by all of the following,” meaning that the patient must exhibit ALL of the above characteristics for their behavior to be diagnosed as autism. Similarly, in the second revision of the new DSM-5-TR, the manual changes the description of autism diagnosis from being “associated with another neurodevelopmental, mental, or behavioral disorder” to being “associated with another neurodevelopmental, mental, or behavioral problem.” Essentially, this change highlights that while clinicians should still use additional diagnostic criteria when applicable, it does not require specifiers to be diagnosable conditions, which helps clinicians indicate co-occurring issues [2].

4. Autism Spectrum Disorder

To formally introduce what autism is, its symptoms, characteristics, and potential reasons for the increase in its diagnosis will be discussed in the following segment. Autism, also referred to as autism spectrum disorder (ASD), includes challenges with social skills, repetitive behaviors, and speech or non-verbal communication, which affects 1 in 44 children in the United States today [3]. Autism is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. It can be diagnosed at any age but is particularly known as a developmental disorder due to the fact that symptoms arise in the first two years of a child’s life. People with autism have difficulty communicating and interacting with others, have limited interests, repeat behaviors, and have difficulty in school or other areas of their lives. The reason that autism is a spectrum disorder is that there is a variety in the type and severity of symptoms. Some common symptoms that are categorized under social communication and interaction behaviors are little to no eye contact, not looking at people when they are talking, showing a lack of interest in activities, not responding or slowly responding to their name, difficulties with back and forth conversations, talking too much, showing facial expressions, movements or gestures that are inconsistent with the topic matter being discussed, an unusual tone of voice, having trouble understanding another person’s perspective or being unable to predict or understand others’ actions, difficulty with adjusting behavior to fit a social setting and difficulties with sharing or making friends. Some examples of restrictive and repetitive behaviors include repeating words or phrases, intense interest in specific topics such as numbers, details, or facts, showing signs of overly obsessive interest in doing
things such as moving objects, being upset with transitions or changes in routine, and being more or less sensitive to sensory input such as light, sound, clothing, or temperature.

While autism can cause severe issues in a child’s development, there are also some strengths that people with autism might have, some of which include being able to remember things in great detail and for long periods of time, being strong visual and sensory learners, or doing well in areas such as math, science, music, or art. Some factors that increase a person’s likelihood of autism have a sibling with ASD, older parents, certain genetic conditions such as down syndrome, or very low birth weight [4].

5. Diagnostic Process of ASD

The diagnostic process of autism spectrum disorder is a two-stage process that requires careful attention to a person’s presented symptoms. While ASD can be reliably diagnosed by the age of two, there are still many precautions that need to be taken to ensure a proper diagnosis. The first stage is called ‘General Developmental Screening During Checkups’, where when the child receives wellness checkups with a pediatrician, they can also get evaluated for developmental delays as recommended by the American Academy of Pediatrics at the 9, 18, 24, or 30-month wellness visits. Additionally, some healthcare professionals will ask questions about a child’s behavior and evaluate them using ASD screening tools. If a child exhibits signs of developmental delay, the healthcare provider might refer them to a psychiatrist or psychologist for additional professional help. During the second stage, it is a crucial aspect of the process to accurately detect and diagnose children with ASD, as well as do it immediately. It is also important to shed light on the strengths and challenges of the child so that other professionals can be contacted in time, as early detection can greatly help caregivers recommend specific services, educational programs, and therapy for behavioral issues to help the child in need [4].

6. Higher Prevalence of Autism

Now, the big question remains: Why has autism spectrum disorder been diagnosed at a higher rate over the past few years? Statistically speaking, autism has steadily risen since researchers first started tracking it as early as the year 2000. As such, this rise in the diagnosis of autism has created issues amongst researchers and clinicians, fearing that there might be an autism ‘epidemic.’ However, many researchers have supported the idea that the diagnosis of autism has only increased over the past two centuries because of the growing awareness of the disorder and the changes made to its defining criteria. The Centers for Disease Control and Prevention (CDC) estimates that 1 in 68 children in the U.S. has autism, 1 in 42 for boys and 1 in 189 for girls, meaning that there is a ratio of 5 boys to 1 girl. As stated, the latest estimate of autism prevalence, 1 in 68, has changed drastically from 2008, when the estimated prevalence was 1 in 88, or in 2000 when the prevalence was 1 in 150. According to Maureen Durkin, the head of the network site in Wisconsin, the increased awareness of autism due to social media and other forms of media has undeniably contributed to the increased rates of autism [5].

Many experts are pressed with this common question; Is there an autism epidemic? The short answer: No, there is not. However, the increase in the autism rate reported by the CDC does, in fact, show that there is an autism diagnosis epidemic. In 2016, 1 in 54 children were diagnosed with autism, while the rate now is 1 in 44.
children. There is a huge debate currently facing experts in this field, as some argue that the increased rate of autism is due to environmental causes such as vaccines, while others argue that the rate is increasing because of the rising age of parents, especially fathers. However, both of these predictions are not based on fact, specifically, because there is very little evidence to support either of these claims [6].

Rachel Burr Gerrard believes that the rise in the autism diagnosis rate is very much social, not biological. Additionally, she thinks that “it's not that more children are developing symptoms of autism, but multifaceted sociological and political factors are increasing the diagnoses and documentation of this condition over other developmental diagnoses.” The first factor that led to the rise in the diagnosis of autism was the rise of the deinstitutionalization movement, which started as early as the 1960s with parent groups such as the National Association of Retarded Children advocating for the normalization of children diagnosed with what was called mental retardation at the time (Note: the term “mental retardation” is very offensive today, but here it is solely used for educational purposes of how people referred to autism during the 1960s. Similarly, sociologist Gil Eyal believed that children with autism lagged behind in only a few areas but could improve with behavioral therapies, while children with mental retardation lagged behind in areas and should, therefore, be banished to institutions. However, as this movement grew, many children who would have been diagnosed with mental retardation were instead diagnosed with autism, not because this diagnosis was more representative of their symptoms but because the treatment for autism was preferred over that for mental retardation.

With the increase in the diagnosis of autism came a decrease in the diagnosis of mental retardation and other learning disabilities. More autism diagnoses meant more patient advocacy, which led to more money for autism therapy and research, leading to even more diagnoses. Additionally, another factor that has led to the rise in autism rates is the passing of certain insurance mandates. Specifically, since 2001, all 50 states have put in place mandates that require non-self-funded private insurance plans to cover behavioral therapies for autism, saving families up to $50,000 a year on treatment. Directly following a state’s implemented mandate, the rate of diagnosed autism rose by 10% and 18% after a few years. These insurance mandates increase these autism rates because of the push for a diagnosis that ensures a child receives coverage for their needs. For example, the families of children with developmental disorders (not autism) rely on broad laws such as the Individuals with Disabilities Education Act (IDEA), which states that each child must receive a “free and appropriate public education in the least restrictive environment.” Congress, however, underfunds this implementation but also depends greatly on the state’s interpretation of this mandate. In 2013, the American Psychiatric Association narrowed its criteria for autism diagnoses, meaning that in its 2018 and 2020 reports, the CDC used both the psychiatric association’s older broad diagnostic criteria and its newer criteria, which greatly increased the diagnosis rate of autism [7].

7. Conclusion

Autism spectrum disorder can manifest in many ways and could possibly be diagnosed differently with each changing definition. It is important to recognize that autism spectrum disorder can be very disruptive to a child’s developmental, social and academic life, and even more crucial to understand autism as an entire spectrum, not only as a short list of symptoms. As autism spectrum disorder becomes more common, many critics say that
there may be an autism epidemic upon us, when in reality, the increase of this diagnosis tells others that proper awareness is being spread surrounding this issue. With the changes in the DSM-5-TR ultimately broadening the scope of autism spectrum disorder symptoms, more and more scientists realize the importance of just two new words in this updated manual. Ultimately, the global increase in autism prevalence is relatively positive, as it reflects the strides the world is making toward raising public awareness for an issue that has regularly been overlooked. In turn, this means that children are being diagnosed with autism earlier and earlier, as technology has been detecting it more accurately and sooner in the developmental process. In conclusion, the growing prevalence of autism spectrum disorder is shown to be more positive, especially for those who require any medical attention or treatment, which is why this disorder is measured on a spectrum, not just diagnoses based on a short list of symptoms.

References


