



HIDDEN IN PLAIN SIGHT: IMPROVING EARLY RECOGNITION AND INTERVENTIONS IN HIGH-FUNCTIONING AUTISM

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ABSTRACT

Autism Spectrum Disorder (ASD) is a heterogeneous neurodevelopmental condition characterized by deficits in social interaction and communication, restricted and repetitive behaviours, and sensory and learning defects. The category includes autistic, pervasive development, and Asperger's disorders, with a spectrum of impairment of symptoms ranging from mild to severe. High-functioning autism (HF ASD) refers to the milder form of the disorder, in which individuals can use language superficially and have a normal or above-average IQ. This milder presentation of ASD often goes unrecognized in females, children with high intellectual capacity, and those with less severe symptoms. Individuals with HF ASD experience difficulties with emotional regulation, and there is a higher prevalence of depression, anxiety, self-harm, and suicide attempts. In addition, HF ASD comes with higher rates of misdiagnosis and psychiatric hospitalizations, and individuals face daily challenges to function in their environment. In order to improve recognition of HF ASD, clinicians should pay close attention to complicated or unclear presentations of ASD. This paper aims to confront the factors contributing to poor recognition of HF ASD and outlines early recognition and intervention improvements.

KEYWORDS: *autism spectrum disorder, high-functioning, neurodevelopmental, disorder, recognition, intervention*

INTRODUCTION

Autism Spectrum Disorder (ASD) is a heterogeneous, highly heritable, neurodevelopmental condition that includes autistic, pervasive development, and Asperger's disorders. It is characterized by dysfunctional social interaction and communication, repetitive behaviours, and sensory and learning defects (1). ASD is a common neurodevelopmental disorder, and diagnosis rates have increased dramatically over the past two decades, with prevalence rates steadily increasing from 1 to 150 children in 2000 to 1 to 44 children in 2018 (2-3).

The category of ASD contains a broad range of impairments, presenting with severe to mild symptoms. The milder form was referred to in the past as high-functioning autism (HF ASD), thus, it will be referred to as such in this article.

The diagnosis's severity depends on the degree of social impairment and repetitive behaviours, criteria outlined in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (1).

ASD is a lifelong condition and is normally diagnosed early, with the onset of symptoms usually presenting within the first three years of life. Behavioural and development presentations are used for diagnosis, including clinical specifiers related to language, movement, adaptation, cognitive skills and comorbidity.

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Autism presents differently in milder and higher-functioning individuals who require minimal daily support. Individuals with HF ASD have average, sometimes above-average IQs and can use language, albeit superficially.

However, the term “high-functioning” is misleading, as it refers solely to the context of autistic disorders. Compared to the general public, these individuals are no longer “high-functioning” and face many challenges regarding their actual ability to function in their environment. People with this type of autism have significant difficulties with emotional regulation (4), higher rates of depression (5), anxiety (6-7), self-harm (8), and suicide attempts (9). In addition, there are higher rates of psychiatric hospitalizations in previously undiagnosed autism (10). For these reasons, it is important to improve early recognition and interventions in HF ASD.

Factors contributing to poor recognition of high-functioning ASD

People with HF ASD have an average or above-average IQ and can use language for communication, although it may be in a superficial manner; this may contribute to a missed or late diagnosis, as a mild presentation of autism is often missed. Females and children with high intellectual capacity are at higher risk for poor recognition. ASD has a prevalence rate of 3-4 males to every female (11), which could affect diagnosis by gender bias. Females may also be less diagnosed due to concealing behaviours, such as masking.

Many factors can contribute to a missed or late ASD diagnosis, including camouflaging behaviours such as masking and mimicking, internalizing behaviours, mistaken social competence, and advanced verbal language skills. Masking behaviours, hiding certain personality traits, may be utilized to adjust to the surrounding social environment. For example, mimicking, the imitation of gestures, facial expressions, movement, and speech, may be used for peer acceptance in social situations. Individuals may have trained themselves to use eye contact, smile, or utilize certain phrases and gestures, for example, for social engagement. These behaviours help individuals “appear to be normal”, camouflage their actual social-communication difficulties, and lead to a mistaken social competence (12-13). Mimicking and masking are commonly seen in females with HF ASD (14-15).

Internalization can result in poor self-esteem and lead to emotional disorders, such as depression or anxiety. In addition, co-occurring psychiatric disorders may conceal the actual neurodevelopmental disorder of ASD, resulting in late diagnosis and improper support.

The complexity of social demands and expectations advances as children grow, so as time goes on, problems may become apparent and result in a late diagnosis.

Presentation of high-functioning ASD

Areas of difficulty in individuals with HF ASD often fall in the following triad: cognitive rigidity, social-communication deficits, and sensory deficits.

Cognitive rigidity is the “inability to mentally adapt to new demands or information” (16). There may be a “black and white” viewpoint, with little space for alternatives, whether that be viewpoints or ideas. In daily life, the inflexible individual may be described as “stubborn”, “defiant”, “difficult”, “does not go with the flow”, “insists on having things done only in a specific way”, and “refuses to cooperate”. They think in literal terms and show difficulties with adapting to unexpected change.

Social-communication deficits present difficulties in integrating social norms and context, as well as social perspective-taking. Social reputation is not recognized and does not serve as a motivator (17). There is difficulty in social contexts in relating to the feelings and beliefs of others, with failure in perspective taking. Someone with HF ASD may be referred to as “unfiltered”, speaking without regard to the situation or individual in their presence. It may be noted that they do not understand sarcasm, due to poor understanding of situational context, communication tone and body language. Instead, metaphors or irony may be interpreted literally and are misinterpreted. Although there may be a desire to engage socially, there may be a failure to initiate interactions due to a lack of social skills (18-19).

Over-responsivity to sensory stimuli encountered in daily life is another difficulty commonly presented. Sensory deficits include sensitivity to food and clothing textures, loud sounds, deep pressure affinity, light, and differences in pain perception.

The individual with HF ASD may be a picky eater, displaying strong food preferences and selectivity. Tactile sensitivity presents with food and clothing preferences, as there may be an inability to tolerate certain materials and textures. In addition, hypersensitivity to human touch may also be present and someone with HF ASD may pull away from light touches or be calmed by deep embraces like hugs. Hyperacusis, heightened sensitivity to sound, can be observed with over-reaction to loud noises that most people can normally tolerate. The individual may cover their ears, become upset, or try to leave the area. Bright lights or certain types of lighting, such as fluorescent lights or LED, may

cause distress. And pain responsivity can be different in these individuals as well, with some displaying hyposensitivity, reduced pain sensitivity, and others showing hypersensitivity, increased pain sensitivity.

The importance of appropriate identification and treatment

It is important to identify HF ASD and initiate treatment as early as possible. Misdiagnosis rates are high for people on the milder scale of ASD. These individuals are often diagnosed with oppositional defiant disorder (ODD), disruptive mood dysregulation disorder (DMDD), bipolar disorder, or borderline personality disorder (BPD), diagnoses which may mask their actual autistic condition and prevent them from receiving proper support (20).

There is also a high level of psychiatric comorbidity with HF ASD. One study of 122 adults with normal-intelligence ASDs revealed that significant percentages of patients experienced depression, anxiety, attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), tic disorders, and psychotic disorder (5). This leads to polypharmacy and higher risks of negative outcomes.

Because an individual with undiagnosed HF ASD can manage and execute daily tasks, they may not be identified as different and are expected to function normally in their environment. There may be minimal to no accommodation by schools or family and support systems, and these individuals are expected to perform with tools they may not possess. The minimal adaptation of the environment and treatments explicitly targeting social pragmatics makes it harder to cope and succeed socially, especially as a child enters adolescence, when demands increase. A misdiagnosis that masks an ASD can create confusion and frustration for an individual regarding their skills and social competence, damaging self-esteem and leading to psychiatric problems such as anxiety and depression.

Improving recognition and support

What can be done to improve the recognition of HF ASD? Because individuals with HF ASD show milder symptoms, recognition and diagnosis can be difficult. They may show a normal IQ and deficits in social interaction and communication may not be immediately visible. Furthermore, coping mechanisms may be used to hide these deficits and appear as “normal”. Therefore, clinicians should maintain a high index of suspicion in cases with complicated and unclear presentations. Subtle signs of social deficits may not be apparent at first, and further observation may be necessary.

The gold standard for diagnosis remains a clinical one using DSM-5 criteria, which outline deficits in social communication and interaction, restricted or repetitive behavior patterns and interests, and gives clear guidelines for diagnosis (1). It is imperative to obtain a thorough developmental history that includes social pragmatics and adaptive functional skills, and it is important to use screening tools, such as the Social Responsiveness Scale (SRS), to aid and support the clinical suspicion. The SRS measures the severity of symptoms regarding mannerisms and social contexts including deficits, cognition, communication, and motivation, and can be particularly useful for identifying autistic traits in milder forms of ASD.

Once a diagnosis is confirmed, support can be improved with therapy intervention, accommodation, the explicit teaching of skills, and modelling of inclusivity and acceptance.

Psychoeducation should follow diagnosis, starting with the child, as well as parents, the school and supports. This aims to improve self-understanding and awareness of autistic symptoms. Awareness can allow for the reframing of behaviors. The difficult behaviors of the individual before diagnosis must be relabeled. Refusal, stubbornness, defiance, and opposition can be redescribed; they now become “unable to” and “doesn’t have the required skills currently to meet the demands being asked”.

The environment should be accommodated to set the children up for success, rather than placing further challenges and difficulties upon their shoulders. Sensory breaks, moments of time dedicated to reducing stimuli overload, can be introduced into the daily schedule. Unexpected changes or transitions can be very difficult for autistic children, so in order to support them any upcoming changes should be previewed. Schedules with routines will help these individuals cope better. Peer models can be very useful as well, as peer-based interventions using typically developing peers as social models have been shown to improve social skills (21).

It is important to teach explicitly what neurotypical children learn implicitly; this includes social pragmatic skills, self-regulation skills, and complex adaptive skills (“street smarts”).

Stigma affects the autistic community but can be overcome by understanding of the disorder. The environment should be a model of inclusivity and acceptance, providing welcoming conditions and opportunities for the autistic individual.

CONCLUSIONS

In the spectrum of autistic disorders, HF ASD presents with milder symptoms and for this it may not be initially apparent. Individuals with this type of autism face many challenges in daily life, where they are expected to perform in

their environment but lack the tools to function. Individuals with HF ASD often have difficulty due to cognitive rigidity, social-communication deficits, and sensory deficits. Communication and social challenges increase as these individuals advance in age, further increasing these challenges and leading to poor self-esteem. They may suffer from depression, anxiety, or other mood disorders, have problems with emotional regulation, and psychiatric hospitalization rates are higher for those who go undiagnosed. For these reasons, it is vital to improve recognition of HF ASD in order to extend support to these individuals.

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Conflict of interest

The author declares that they have no conflict of interest.

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