Case Report

Seeking Social Connection and Knowledge as a Minimally Verbal Autistic Male with Intellectual Disability

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Article

Seeking Social Connection and Knowledge as a Minimally Verbal Autistic Male with Intellectual Disability

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Abstract: We bring a strength-based and socially-oriented lens to behaviors observed in profound autism. Social deficits are a defining characteristic of autism. Yet humans' biological drive for social connection is sufficiently strong that it should be observable, in some form at least, in individuals with autism. We describe a case that validates this view. Mahad is a 20-year-old Pakistani-American male, with intellectual disability, and minimal verbal abilities. Mahad has an intense interest in food and the steps involved in food preparation. He employs and capitalizes on his family's meal routines to ensure continual social attention from his mother. When not immersed in food, Mahad uses his limited capacities to pursue the additional biological needs of exploring his environment, seeking information, and developing his cognitive abilities.

Keywords: profound autism; social connection; special interests; cognition; adults; sociality

1. Introduction

Psychologists are unanimous that there can be no robust mental health without intense, life-long sociality (Turner & Brown, 2010). Failure to attain expected social attachments is a risk factor for compromised health throughout the lifespan, from peer rejection in childhood to loss of a romantic partner in adulthood (Crouch et al., 2019). Each life stage is replete with specific and varied mechanisms to create a bi-directional attachment to parents, play relations with peers, mentorship from experts, and so on. But what happens to the social drive when an individual has a severe mental disability? One expects the biologically based, evolutionary-honed drives for social connection will still be present, but their manifestation will be constrained by the extent of intellectual disability (Nota et al., 2007).

Here we proceed an additional step beyond intellectual disability. What happens to social drives when intellectual disability is part of autism? A defining feature of autism is social impairment. Controversy reigns in describing the nature of this impairment (Jaswal & Akhtar, 2019). Is sociality absent? Some characterizations of autism have depicted an apparent absence of social interest (Baron-Cohen, 1997; Hirstein et al., 2001). Other theorists have described sociality as reduced (Chevallier et al., 2012; Frith & Frith, 2011) or atypical in poorly understood ways (Dawson & Cowen, 2019; Caldwell-Harris & Schwartz, 2023).

We were inspired by a young adult (Mahad) with profound autism. Mahad is minimally verbal with severe intellectual disability. We will describe how Mahad developed routines to creatively and relentlessly build social interactions with his parents. Yet Mahad's strong social drive does not create a simple story of happy family interactions. In pursuit of social connection, Mahad frequently created time-consuming demands on parents, leading to aggression and chaos in the household. Nonetheless, by emphasizing sociality, we challenge the conventional view of social disinterest in autism. We additionally note how Mahad uses his limited capacities to pursue the additional biological needs of exploring his environment, seeking information, and developing his cognitive abilities.

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2. Detailed Case Description

The subject, Mahad, is a 20-year-old Pakistani-American non-verbal autistic male from a low-income household living with his parents, older sister, younger brother, and aunt in a one-bedroom apartment in Central New Jersey. He is part of a traditional South Asian household in which his mother is the primary caregiver and his father is the family breadwinner. Mahad is the second child to his parents and was diagnosed with autism when he entered pre-school. His family was concerned about his speech delay but was reassured by family friends and the primary care physician that some children take longer to learn speech than others. Having an intellectual disability is stigmatized in South Asian communities. Immigrant families sometimes overlook delayed development rather than grapple with the possibility of stigma associated with neurological differences. Mahad's parents also knew little about autism. They may have failed to notice social deficits probably because Mahad hung around his older sister and often imitated her. However, at his entrance to preschool at age 4, Mahad's teachers alerted his parents about their son's language and social challenges. Specifically, they noticed his inability to interact with his peers at an age-appropriate level. Mahad's parents were devastated upon learning that their son "was not normal." His father even took Mahad to spiritual leaders paranoid that someone may have performed witchcraft on him. It should be noted that although Mahad's father is a devout Muslim, he believes in witchcraft, which is controversial in Islam. His father also places a lot of blame for the autism on Mahad's mother, failing to understand its genetic underpinnings. These issues may have interfered with seeking early intervention and with psychoeducation that could have been made available.

Mahad exhibits the classic symptoms of autism mentioned in the DSM, such as deficits in social communication and restricted and repetitive behaviors. For example, he cannot engage in social-emotional reciprocity and does not use gestures or facial expressions to express himself non-verbally. Mahad's vocabulary is limited. He repeats the same few words or phrases to communicate. The bulk of his vocabulary consists of words for food, consistent with his special interest in food, discussed below. Mahad also has the classic symptom of resisting change. For example, Mahad hid from his newborn brother for several weeks after his brother's birth. Other examples include his insistence on only sitting in his eating chair and his constant rearranging of items that have been misplaced around the home.

2.1. Interests, Activities, and Coping Strategies

Mahad's interests revolve around food, car rides, and walks. All three are obtained via frequent demands to his parents. When he is not attending a day program for young adults with special needs, Mahad paces around the apartment, following his mother and demanding that she give him food by constantly repeating the phrase "make it" in Urdu (his mother knows that "make it" refers to noodles). If his mother does not go to the kitchen and start preparing food, he begins frustratingly pacing back and forth and crying. Mahad expects his father to take him on a car ride multiple times daily. He repeatedly says "dad's car" in Urdu until his father has no choice but to take him on a car ride around the neighborhood. He demands that the music be turned on as soon as he sits in the car, by repeatedly saying the words "radio" [in English] or "song" [in Urdu] until his father turns on the radio (channel 10.35). When his father is unavailable, Mahad expects his mother or home health aide to take him on walks around the neighborhood or to the basement so that he can pace. He repeatedly repeats the word "outside" (in English and/or Urdu) or "basement" until he is taken out.

Mahad becomes frustrated when his parents spend time with his other siblings and do not give him their undivided attention. He initially expresses his attention by making his usual demands as described above. If Mahad does not get what he wants, he begins to cry incessantly and pinch his face. These are indicators that he is about to be destructive (e.g., hit someone, or throw furniture). Mahad cries incessantly and throws tantrums until his mother prepares his food or his father takes him on a car ride. Mahad is also aggressive. He pulls his mother's hair, bites her, or destroys furniture. His aggression and tantrums cause his mother and the whole household to drop what they are doing and attend to him. This suggests that Mahad intends to direct attention toward himself. He also

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commands attention by wetting his pants or flooding the bathroom so that his mother is forced to clean it up, diverting her attention from other people and activities.

2.2. The Diverse Functions of Food

Food is the most important object in Mahad's daily life, playing three diverse roles: socialization, systemization, and hyperfixation. Rich in spices and robust flavors, meals have a central place in Pakistani culture. Sharing traditional meals allows Pakistani-Americans to emphasize their culture of origin despite their residence in the US. The importance of food for the family may have been a starting point for Mahad's diverse attraction to food and meals. Interviews with Mahad's family suggest that Mahad uses food to connect with his mother, as most of his communication with her revolves around his meals. He only eats food prepared by his mother except for pizza, which he only eats from Dominoes. When Mahad wants food, he repeats the name of the food so that his mother goes into the kitchen to heat it for him. He follows her into the kitchen and plays an active role (e.g., mixing the pot; and taking condiments from the fridge) as she prepares his plate. Mahad is adamant about routines around his food preparation and will not start eating it until his plate has a variety of desired components.

Mahad diversifies his meals by mixing and matching seemingly odd combinations. Mahad repeats the names of the condiments he wants on his plate until his mother adds them. Embellishments include various homemade sauces and salads. Mahad diversifies his foods with different condiments to complete the meal, an example of flexibility and creativity. However, he demonstrates inflexibility by only eating homemade foods, mostly home-prepared curries. While Mahad will only consume certain foods, he embellishes those specific foods in different and sometimes novel ways.

Mahad asks for food multiple times a day, even past midnight. He also asks for food when he is not hungry (such as shortly after a previous meal) because he knows that his mother will not ignore his demands. Mahad uses food and his mother's devotion to him as a way to exert his autonomy while garnering his mother's attention. Once he begins eating, his behavior changes dramatically and he ceases interacting with others. However, it is important to note that Mahad does not overeat, and has been thin and underweight all of his life. He often hyper-focuses on his plate when eating and is not interested in his surroundings. Mahad does not respond if anyone tries to talk to him while he is eating.

3. Discussion

3.1. Implications for Understanding Intense Interests

Mahad's interactions with food serve the human need to socially connect with others and also suggest a new way of thinking about the purpose of intense interests. These were historically called restricted and circumscribed interests, but are referred to in the strength-based literature as special interests or intense interests (Caldwell-Harris & Jordan, 2014; Grove et al., 2018). Researchers have posited that special interests are used to reduce anxiety (Atwood, 2003) or reduce over-arousal caused by sensory stimuli (Hutt et al., 1965), but autistic individuals engage in repetitive behaviors and special interests even when alone and unstimulated (Turner, 1997). We argue that special interests broadly serve the purpose of knowledge-seeking (Caldwell-Harris, 2021). For autistic youth and adults with normal or superior cognition, intense interests resemble the systemizing and discovery processes of scholars and scientists, consistent with the literature on autistic inventors and scientists (Silberman, 2015). But knowledge seeking can still be present in autistic individuals with intellectual disability. Repetitive behaviors are a form of experimenting in the world to gain knowledge. The autistic individual repeats actions with minute variation, to observe the effect of a slight change (Caldwell-Harris, 2021). One can repeatedly manipulate objects, noticing the new information from vision and touch.

A knowledge-seeking drive may be most easily channeled into examining objects' affordances, by repeatedly manipulating them and comparing them, as in the classic symptom of lining up objects.

 doi:10.20944/preprints202403.0338.v1

As many have observed, autistic children do vary their repetitive behaviors, "mixing things up," looking at an object from different angles, varying a motor trajectory, or looking for varied objects within a specific domain (storm drains, WWII biplanes; Winter-Messiers, 2007).

The domain of an intense interest will need to be something in the child's environment that is amenable to systemization (Baron-Cohen, 2020). Here we discuss how food preparation serves Mahad's two main drives: (a) to exercise his cognition via systemizing and experimentation, and (b) to connect socially with caregivers.

Living in a small apartment, cared for by his mother, Mahad has spent his life watching the several times-per-day ritual of food preparation. He has seen the food preparation process enough times to extract and predict its regularities. Skillful imitation is a hallmark of human nature (Tomasello, et al., 1993). Mahad has scrutinized and watched food preparation and has extracted its salient components. He now varies the food preparation steps to maximize cognitive stimulation and social connection.

3.2. Implications for Understanding the Affiliative Drive

Mahad appears to have a high desire to socially connect with caregivers. His mother preparing food for Mahad is a reliable daily event where his mother focuses attention on him. We propose that this reliable attention, combined with Mahad's social drive, caused him to hyper-fixate on food. Intense interests and hobbies allow neurotypical children and adolescents to connect with others (Werner, 1993). Theorists have viewed intense interests as socially isolating due to restricted focus (e.g., Anthony et al., 2013). In contrast, Mahad's case is an example of how intense interests can be recruited to serve social connection.

Evidence that Mahad craves attention is his constant demands on his mother, including negative attention seeking. Centering on food is an efficient strategy for gaining positive interaction time with his mother. The evidence that food facilitates social connection with his mother is that Mahad insists on only eating food his mother prepares, thus ensuring her attention. Mahad's rituals with his food have both sameness and variety, consistent with our claim that what has conventionally been called repetitive behaviors can also serve knowledge seeking, albeit constrained by limited cognitive ability (Caldwell-Harris, 2021). Evidence that demands for food, and rituals with food, serve social connection is that Mahad asks for food multiple times a day, independently of hunger. It is an open question why Mahad ceases interacting with others and focuses on his plate while eating. This may be a component of monotropism (Murray, 1992).

3.3. The Strengths of the Strength-Based Perspective

The traditional deficit perspective would identify the deficits in Mahad's behavior as summarized in the left-hand panel of Table 1. A deficit perspective allows clinicians to focus on ameliorating symptoms. To showcase the insights from the strength-based perspective, we summarize on the right-hand panel of Table 1 how Mahad's behavior represents his attempts to achieve foundational human needs despite intellectual disability. Mahad has goals similar to those of NTs: to exercise his cognitive abilities and make social connections.

 doi:10.20944/preprints202403.0338.v1

Table 1. Contrasting perspectives on Mahad's autistic characteristics.

	Deficit-based perspective	Strength-based approach
Overall Profile	The patient has intellectual disability; social impairment, and repetitive routines. Constant supervision is needed.	Mahad uses his limited cognitive and social abilities in pursuit of recognizable goals.
Language	Limited spoken vocabulary; repeats the same few words or phrases (echolalia)	Consistent with the gestalt language perspective (Pizant, 1982), Mahad uses spoken phrases to attempt to communicate to his family members.
Intense Interests	Circumscribed, restricted, repetitive; may help the individual self-regulate, but disrupts family life and are sometimes alien in nature to neurotypicals	Concerns a domain (food) that Mahad can observe and participate in multiple times per day. Mahad can use food to socially engage his mother; Interactions include variation in the form of miniature experiments with food.
Social	Due to intellectual disability, has impoverished relationships that include self-serving demands and aggression against parents	Finds diverse methods to engage his parents in interacting with him, such as: requests car rides with his father; implores his mother to prepare meals
Daily activities	Unable to occupy himself; makes demands throughout the day and night on family members	Mahad's demands create social connection, alleviate boredom, and provide cognitive stimulation, such as being able to experience the outside world.
Aggression	Aggressive with family members, including biting, pulling mother's hair; destroys furniture, disrupts household, wets himself.	Similar to non-autistic youth, aggression serves negative attention seeking, venting frustration. Aggression disrupts boredom and establishes agency.

Intellectual disability is a barrier to Mahad imitating activities such as writing and using technology like his siblings, but his skill set allows him to copy eating. We argue that Mahad developed food and eating rituals to interact with others. When anyone in the household is eating, Mahad wants to eat with them again even if he has already eaten and is full, showing mimetic desire. Mimetic desire is part of being human and includes wanting to do what other people do by imitating them (Burgis, 2021).

Parents often struggle with their autistic children's special interests due to their intensity (Mercier et al., 2000). Mahad's activities with food do challenge his mother's daily life. However, his rituals around food reveal how Mahad employs his cognitive abilities to meet his systemizing needs as a human being. Food is something visible and accessible to him. Orienting around food allows to be an active participant in the household. Mahad may lack social understanding as evidenced by his demands on his family and frequent aggressions, but examination of how he interacts with food suggests Mahad has discovered an avenue that facilitates social connections and allows him agency in his social interactions.

This case study illustrates that special interests exist for more than stress reduction or to avoid demands (Caldwell-Harris, 2021). Instead, interests serve the human need for cognition and the human need to employ one's cognitive resources. Our argument is that even when brain functions are compromised due to debilitating intellectual ability, fundamental drives remain. In this case, these are drives to acquire and manipulate knowledge acquisition, and the drive to affiliate with other humans.

What Mahad does is not so different from what the rest of us do. We all exercise our brains by engaging in activities that serve evolutionarily-relevant goals. The only difference is that he does it through his limited special interests and we do it through our many different social outlets.

3.4. Implications for Autism Theory and Research

The majority of autism research focuses on the impairments of autistic people relative to non-autistic people and rarely acknowledges their strengths, abilities, and social potential (Bottema-Beutel et al., 2023). Autistic research has also historically lacked ethnically and culturally diverse samples (West et al., 2016). Autistic people are often described as missing core human abilities (Gernsbacher, 2007) and as incapable of social reciprocity (Botha & Cage, 2022). Botha & Cage (2022) examined how autism researchers characterize autistic people and discovered that two-thirds of the research was ableist toward autistic people as it used dehumanizing, objectifying, and stigmatizing language. Most autism studies are behaviorally oriented, focusing on how to change participants' behavior but they do not account for how successful these interventions are (Bottema-Beutel et al., 2022). Focusing solely on deficits in autism does not accurately represent autistic experiences (Cowen et al., 2009), as autistic accounts of autism are much broader in scope and more holistically shed light on strengths and challenges (Sinclair, 2012; Russel et al., 2019).

 doi:10.20944/preprints202403.0338.v1

The deficit approach is also present in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Disabilities (ICD) (Bottema-Beutel et al., 2023). The deficit model of autism contributes to the dehumanization, pathologization, reductionism, and essentialism of the experiences of autistic individuals (Kapp, 2019), promoting the idea that autism is a condition that needs to be "cured" by scientists and clinicians. Many autistic individuals have expressed concerns about scientific research on autism focusing on cures (Daley et al., 2013). Hypotheses such as the theory of mind that argue that autistic people are unable to understand the feelings and emotions of others (Baron-Cohen,1985; Yergeau, 2013) further purport the idea that autistic people are lacking (most destructive to low support needs). This hypothesis may be especially harmful to intellectually disabled non-verbal/minimally verbal autistic individuals like Mahad who are often excluded from autism research (Jack & Pelphrey, 2017; McKinney et al., 2021; Russell et al., 2019; Tager-Flusberg & Kasari, 2013). The difficulties of this group of autistic individuals have been under-researched and there is currently no recommended intervention to ameliorate their struggles (Brignell et al., 2018; Koegel et al., 2019; Russell et al., 2019).

However, since Jim Sinclair's paper "Don't Mourn Us" (Sinclair, 2012), researchers have incorporated the feedback of autistic individuals in their work (Hart, 2014). The "neurodiversity movement," which challenges the deficit model of autism, has become influential (Kapp et al., 2013). Autism research has mostly focused on the individual, with very few studies on social interaction in autistic people (De Jaegher, 2013). A neurodiverse perspective on social relationships challenges the normative outcomes for social relationships acknowledges the struggles of autistic individuals and presents them as strengths and differences as opposed to inherent deficits (Baren-Cohen, 2017). Therefore, instead of attempting to "cure" autism, researchers should focus on lessening the effects of negative behaviors and improving the overall quality of autistic people's lives.

Caldwell-Harris and Jordan (2014) proposed that people form special interests in specific areas due to their unique cognitive abilities in systemizing and mentalizing. Adopting a strength-based approach can allow researchers, clinicians, and educators to leverage autistic individuals' special interests to teach important skills (Caldwell-Harris & Jordan, 2014).

4. Recommendations

Mahad's case demonstrates that special interests can be used to process information and demonstrate cognitive strengths. By identifying which behavior serves what category of human needs, providers can reframe autistic characteristics to improve autistic people's overall quality of life. We can make a comparison to how the autism research community reframed their understanding of echolalia in the last decades (Prizant & Rydell, 1984) in recognizing that many autistic children repeat overlearned phrases as a communicative technique with caregivers. Echolalia has been reframed from a deficit to be eliminated to a sign of communicative desire. Speech pathologists have therefore encouraged parents to treat echolalic phrases as communicative signals. A client-focused therapy could be devised to teach autistic people how to use their interests to have their needs met.

When confronted with negative attention seeking, parents are exhorted to "refill their child's emotional bank account." The implication is that if Majad's social needs are more robustly, he will have less need to act out in order to gain attention. Rituals around food suggest a starting point for more regular engagement. While his mother prepared food, Mahad could be invited to stir a pot, or do other meal preparation actions that are slightly out of his comfort zone and which he might initially reject. Therapists and caregivers could demonstrate food-adjacent activities, such as handling play food, re-arranging food in a kitchen family; leafing through books with photos of food.

Special interests can be enlarged. One rationale for this is that autistic adults with typical intelligence can have diverse, complex interests, with an interest in one area leading them to a related area (Caldwell-Harris, et al., 2022). Autistic adults with typical intelligence learn on their own how to enlarge their interests. However, individuals with limited intellectual abilities may need outside modeling and guidance. A current hyperfixation can be the starting point from which interests are expanded into adjacent areas. Clinicians and family members can brainstorm about what adjacent areas might be appealing, and use these to help the autistic person expand their interests.

 doi:10.20944/preprints202403.0338.v1

Although obviously profoundly autistic, is Mahad more social than the norm for autistic children with his level of disability? To investigate this further, our team is currently running a small-N study of young adults with Mahad's profile of low verbal ability and intellectual disability. Comprehensive interviews with parents will follow the strength-based approach outlined in the current case study.

5. Conclusions

This case study demonstrated how a minimally verbal autistic young adult used his limited capacities to pursue the biological needs of ensuring relationships with others, exploring his environment, and developing his cognitive abilities. The strength-based approach reveals behaviors that are on a continuum with neurotypical behaviors. We are not making the error here of asserting that autistic individuals resemble neurotypical individuals. Rather, we argue that evolution has put in place drives in humans to acquire knowledge and affiliate socially. These drives will still be operative but altered due to intellectual disability, lack of fluent language, limited socialization due to intellectual deficits, and aspects of the autistic phenotype.

In this case study we shed light on strategies that minimally verbal autistic youth and adults may use to socially engage family members through direct social engagement (similar to neurotypical behavior) but also routines, intense interests, negative attention seeking, and aggression. Mahad used his special interests to pursue social connectedness and novelty.

Sociality varies in all humans. Autistic individuals have heterogeneous abilities. Mahad's social drive may be more intense than other autistic young adults. Our point is that this case study is at odds with the mainstream view that autistic individuals are socially incapable and have low social drive. Consistent with Jaswal and Aktar (2019), the questions and findings suggest new conceptualizations and open the door for combining sociality and special interests in autism treatments.

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