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ORIGINAL ARTICLE

Resisting the Pathologizing of Autistic Eating

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Abstract

Autistic people live in a world that pathologizes their every action, not the least of which are their limited diet preferences and selectivity for certain types of food. The result is the assumption that many, or even most, autistics have an eating disorder or a feeding disorder. I examine this assumption by looking at the literature that describes autistics' mealtime rituals and preferences for familiar foods. These rituals are often the result of, and a means to reduce, the sensory overloads that mealtimes represent, an overwhelming confusion of tastes, smells, textures, and sounds. Rituals, same foods, and moving around can help autistics cope. These preferences can be as simple as a preferred seat at the table, specific cutlery, foods not touching or on separate plates, or presenting a hot dog in a bun despite the child never eating the bun. Food neophobia, a refusal to try new foods, is also a well-known autistic trait, and often a source of contention between autistics and allistics (non-autistics). I contend that while these behaviours are often understood as rebellion, stubbornness, picky eating, or other forms of misbehaviour, they are not eating disorders. Autistics ought to be allowed to choose how, when, and what they eat. Treatments to alter autistic eating attempt to re-order the autistic in accordance with dominant eating orders. Such corrective and coercive measures are justified by the argument that if allowed to eat as they wish, autistics will be harmed, such as by missing out on the pleasures of social sharing or disrupting the serenity of the family. I argue that autistic eating preferences should not be pathologized, and I call for a radical autistic scholarship, done by autistics, that starts from the perspective that we do not have a disorder.

Keywords

Autism, autistic eating, mealtime rituals, autistic preferences, feeding disorder, food neophobia, samefooding, critical eating dis/order studies

History

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My Son

My son is a 17-year-old autistic ADHDer, (a.k.a. AuADHD) and I write this with his consent and knowledge. He was a picky eater as a child, but we never forced him to eat foods that he refused. We did have a rule that he had to try one bite (usually a rabbit sized nibble), but that after doing so he was free to refuse any more. Did this cause us to have to make extra meals for him? Sure. Was it aggravating to me, someone whose family had a mandatory family dinner every night, for him to walk around while eating? Yes, but I managed to survive. Even now, he often will take dinner into his room to eat alone, but boy does that kid eat. And for his 17th birthday he was the one who wanted to try different restaurants and different types of food. By not forcing him to clean his plate, by not demanding he eat what everyone else was eating, by not cooking meals I knew he would hate, he was raised with a healthy attitude towards food and a willingness to at least try new things. I remember texting my wife with pride when at 7 years old he ate my bock choy chicken soup after taking the required taste and finding it agreeable. And as I write this, less than an hour ago I showed him how to make crock pot beef stew so he would be able to feed himself cheaply and easily next year when he goes away to university. Rather than pathologizing his needs, I treated them as the choices made by a human being with the right to their own autonomy. Some of his needs I understand intuitively as a fellow autistic, but some come from his ADHD and I don't understand. But even without *understanding* his needs I was able to *respect* them as much as possible. Sometimes that means he eats an English muffin with cream cheese for breakfast every day (until we lay in a large supply of English muffins and he never eats them again. The same with a particular brand of breakfast cereal filling my pantry). And as he got older, he took on more responsibility for preparing his own alternates when he didn't want to eat what the rest of us were having, or didn't want to eat at the same time we did. We taught him to make sandwiches, toast, grilled cheese and other easy items, but the just-add-boiling-water instant noodle bowls are still his go-to. And that is OK, despite the high sodium, because he also eats the healthier meals I make. But on his own time, in his own way.

Understanding Autistic Eating

The psychiatrizing of eating preferences

To be autistic[1] is to have a disorder in the eyes and minds of others. That which might be a normal preference in a 'normal' person is automatically pathologized. In the DSM-5, the current manual for deciding who is pathologized and who is not, subcategory 3 of criteria B for an autism diagnosis is "Highly restricted, fixated interests that are abnormal in intensity or focus." (Neff, n.d.). For autistics, behaviours and preferences around mealtimes and food become viewed as eating disorders that are further indications of a mental health disorder. In this article, I begin by drawing on the academic literature on the preferences of autistic

[1] For an explanation of why autistic people prefer identity-first language see (Brown, n.d.; Gernsbacher, 2017)

eaters around mealtime rituals and preferences for familiar foods. I then outline others' corrective responses to these preferences. Finally, I make the case that autistic eating is pathologized and argue that autistics' eating preferences should be accepted and respected.

Mealtime Rituals

Mealtime can be discomforting for autistics, who thrive on consistency and routine. As Kuschner et al. (2015) note, this is an especially variable time, as foods, utensils, dishes all change while autistic people can have difficulties with novelty, prototype formation, and understanding how to act in a new social context. The selectivity of an autistic person's consumption is a way of spontaneously dealing with the unpredictability of mealtimes by reducing the number of adaptations required (Petitpierre et al., 2021) and/or selectivity is a way to reduce their sensory load. But this desire to protect themselves from overstimulation is often seen as an attempt to control their environment, which is interpreted as defiance and further evidence of the individual's disorder. Autistics' preference for sameness may result in their need for a consistent mealtime routine (Kinnaird et al., 2019). They may feel self-conscious or embarrassed by their eating habits and choose to eat alone or only with people they are close to (Kinnaird et al., 2019). They may also be discomforted by the sounds of people chewing (misophonia), prefer eating while engaging in distracting activities (such as reading, watching TV, or listening to music), insist on a specific chair, or move around as they eat (Huxham et al., 2021). This can cause conflict when family members demand the child sit still at the table and eat in the "proper" way.

Given these challenges, many autistics rely on rituals around food, meals, and mealtimes. Mayes and Zickgraf (2019) list some of the rituals they encountered:

> smelling food before eating it and demanding that food be presented a certain way (e.g., using a specific plate or cup, insisting that foods not touch other foods on a plate, and eating food only if served a particular way, such as eating a banana only if it is peeled after given to the child and eating a hot dog only if on a bun, even though the child never ate the bun) (p. 240).
>
> Reference/identifier

The way food is plated or served can also have an effect. Cermak et al. (2010) cite Schreck and Williams' (2006) who argue that most of food selectivity could be attributed to presentation (such as foods touching, or preferred utensils).

An incident that caught the public's attention - and exemplified this need for consistency - was the 2016 story[2] of Ben Carter of Devon, U.K. and his sippy cup. Ben would only drink

[2]https://www.cbc.ca/radio/asithappens/as-it-happens-tuesday-edition-1.3872769/how-the-internet-came-together-to-find-a-sippy-cup-for-autistic-teen-1.3872772

from the cup he had been using since the age of two, a model that had been discontinued by its manufacturer Tommee Tippee a decade earlier. Ben would only drink from this cup and would only drink when eating. After his father reached out on social media to try and find a replacement, Tommee Tippee received as many as 50 tweets a minute demanding they help. The company managed to find the mold for the cup and made Ben 500 of them, making this a feel-good story and excellent corporate public relations.

Preferences for familiar foods

Autistics' preference for sameness can make them reluctant to experiment with new or unfamiliar foods, resulting in a diagnosis of neophobia, the fear of new and unfamiliar things. Like mealtime rituals, neophobia can also be viewed as evidence of an eating disorder. Kuschner et al. (2015) found that the parents of autistics who self-identified as food neophobic rated their children as less capable in daily living and practical skills than parents of those who did not report issues with trying new foods. The authors proposed that this may be a "manifestation of broader anxiety or difficulties with novelty," meaning autistic people may "struggle with new situations in daily life (e.g., paying a store clerk for a purchased item)" (p. 57). Food neophobia was reported by almost all parents in another study, with 88.5% of the parents reporting that their children had severely limited food preferences (Mayes & Zickgraf, 2019). In the same study, in addition to resisting trying new foods, they also found that many autistics will only eat a specific brand of food, reported by 27% of parents in Mayes & Zickgraf 's (2019) study. This phenomenon, coined "samefoods" or "samefooding" (Kinnaird et al., 2019) refers to eating the same item or items every day, or even at every meal. An autistic person might have the same cereal for breakfast every morning or eat chicken fingers for dinner as often as possible. While many people have preferred meals, the scholars frame it as "disconcerting that parents/caregivers reported that the majority of children (75.6%, n = 223) would repeatedly choose the same foods from a limited range during meals" (Huxham et al., 2021, p. 3). Engaging in samefooding is a way for autistic people to reduce the overall drain on their energies caused by constantly navigating a hostile sensory landscape. As such, eating foods in this way helps the individual meet their sensory needs. When compared to non-autistic people who are deemed to be "picky eaters", autistics "have significantly greater behavioral problems and particular sensitivity to social and non-social stimuli." (Petitpierre et al., 2021, p. 213). Baraskewich et al. (2021) describe a picky eater as someone with restricted or selective food intake that may have: sensory sensitivity to texture, colour, temperature; neophobia; or just limited preferences. When asked what factors influenced their food choices, Cermak et al. (2010) reported that the number one factor was texture (69%), followed by appearance (58%), taste (45%), smell (36%), and temperature (22%). It is also possible that some of the reluctance to eat specific foods could be because of the practical mechanics of eating the food. Kinnaird (2019) notes that there can be physical difficulties around chewing or utensil use due to reduced fine motor skills, or gastrointestinal difficulties that are often associated with autism. Research has shown that the limited diets of autistic people are not the result of low appetites. Cermak et al. (2010), citing a study by Williams et al. (2000), noted that

while 67% of surveyed parents reported their autistic child was a picky eater, 73% of the parents reported that their child had a good appetite when provided food they liked. Likewise, Marí-Bauset et al. (2014), citing Kerwin et al. (2005), found that while more than 60% of autistic children had strong food preferences, only 6.7% did not have an appetite. This suggests that picky eating is not the result of a disordered appetite; rather, it is related to food preferences.

Yanagimoto (2020) claims that "restricted eating … especially in ASD [Autism Spectrum Disorder]" (p. 3) can result in "severe malnutrition leading to stunted growth" (p. 1). Some researchers believe that some autistics meet the diagnostic requirements for avoidant/restrictive food intake disorder (ARFID), a persistent form of picky eating that is characterized by a limited number of foods the individual will eat (Baraskewich et al., 2021). Mayes and Zickgraf (2019) argue that autistics generally are not diagnosed as having AFRID because they do not have the "concern about aversive consequences of eating" or a "lack of interest in eating food." Rather, they meet some criteria because of their "avoidance based on the sensory characteristics of food" (p. 81). Despite this, they noted that autistic children with disordered eating behaviours were not "significantly more likely to be underweight," unlike those who have a diagnosis of anorexia nervosa or ARFID which are characterized by "significant weight loss or failure to achieve expected weight as DSM-5 diagnostic criteria" (p. 81).

Because one of the difficulties autistics face is hypo- and hyper-sensitivity, researchers theorize that the feeding difficulties can be attributed to sensory processing disorder. Kinnaird et al. (2019) suggest that aural hypersensitivity (e.g., cutlery scraping on plates, large numbers of people talking at once) might account for autistic discomfort in communal eating areas, while Marí-Bauset et al. (2014) cite multiple studies that found smell and taste hyper-sensitivities in autistic children. In a study identifying children with oral sensory sensitivity and oral sensory over-sensitivity, Chistol et al. (2018) found that the number of autistic children with atypical scores for oral sensory sensitivity (64%) and oral sensory over-sensitivity (66%) was vastly greater than that of allistic (non-autistic) children (7% and 9%, respectively). Further, those with atypical scores in oral sensory/over-sensitivity consumed a significantly lower variety of fruit than those who did not, while those who scored as atypical in both measures consumed a significantly lower variety of vegetables than those who scored in the typical range for both. Sensory sensitivities can also influence food choices due to the mechanics of eating. Huxham et al. (2021) report that a majority of children (60%) disliked getting their hands or face dirty, and 72% disliked strong smells. The authors note that autistic children may avoid a food "not because they do not like the way it looks or tastes, but possibly due to how it feels and the effect it has on their hands afterwards" (p. 5). They might avoid sticky foods eaten with the hands, such as chicken wings or spareribs, might wipe their hands and/or face after each mouthful, or eat foods with utensils in unusual ways, such as using a knife and fork to eat pizza.

Feeding Disorders

Baraskewich et al. (2021) note the difference between eating disorders and feeding disorders: “eating disorders involve varying degrees of preoccupation with food, body weight, and/or shape” while feeding disorders may be motivated by “a combination of other reasons (e.g., negative previous feeding experiences, pain/discomfort with feeding, and low muscle tone)” (p. 1506). There is no formal definition of a feeding disorder, but Baraskewich et al. (2021) claim it is commonly accepted as a severe disorder of *nutritional intake* not attributed to typical variations in hunger, food preferences, or interest in eating. This would imply that autistics do not generally have eating disorders, but *feeding disorders* because they wish to control how, when, and what they eat.

Corrective Responses to Autistic Eating

The proponents of the need to correct these feeding disorders argue that a number of potential harms can result from not eating a wide variety of foods. They argue that this can spoil the pleasure autistics could “have during meal times and make them miss opportunities for social sharing, social participation, …[and] relaxing in the company of others”, potentially posing a threat to the serenity of the family (Petitpierre et al., 2021, p. 210). Such ‘hardships’ for autistics are not limited to the family dining table, as their “picky eating” may limit potential outings with friends and opportunities for advancement of practical/daily living skills” (Kuschner et al., 2015, p. 57).

When parents attempt to force an autistic child to eat the foods they believe are appropriate, they often face resistance as the child refuses to comply. Applied Behaviour Analysis (ABA) is the “gold standard” of “evidence based” interventions in this regard. One method used by ABA practitioners when trying to “fix” a “disordered” autistic child who spits out a bite of an unpreferred food is called “re-presentation”, which “consists of scooping up the expelled bite, or a new bite of the same food, and redepositing it directly into the mouth.” (Scotchie & Borrero, 2023, p. 357). Scotchie & Borrero (2023) suggest that while there is “the potential for unsanitary conditions related to scooping up the expelled bite … re-presentation of expelled bites has been shown to be an effective intervention…” (pp. 373-374). Some who study the use of ABA on autistics note the poor quality of ABA research and the lack of concern with harm or consent (Bottema-Beutel, 2023; Bottema-Beutel et al., 2021). Another approach used with autistic children is “food chaining”, the goal being to expand the child’s willingness to just try new things; - “consumption is not the primary goal of food chaining” (McHugh, 2019, p. 17).

Parents and caregivers of autistics often seek ways to reduce ‘inappropriate behaviours’. This can impact an autistic person’s access to food. Kinnaird (2019) notes that sometimes parents, in trying to improve gastro-intestinal symptoms, change behavior. Or, in search of a “cure” for autism, parents may restrict the diets of their children, for example by eliminating gluten or casein.

Resisting the Pathologizing of Autistic Eating

Intolerances for, and corrective responses to, autistics' preferences around mealtimes and food consumption bring into high relief the rigidity and prevalence of dominant eating orders in society. Even though autistics are not typically classified as having eating disorders, they are often thought to have feeding disorders because they wish to control how, when, and what they eat. Autistics' preferences take on the status 'disordered' based on their relationship to what is deemed to be 'normal' (allistic). While many people have favourite foods, this is viewed as a problem when autistics do because any attempts by autistics to satisfy preferences tend to be pathologized. When autistics, who are framed as abnormal because of their autism, want to avoid the unpredictability of mealtime or choice of food, they are viewed as 'out of order' or disordered (i.e., inappropriate, controlling, or manipulative). Indeed, once labelled as autistic, a person's mealtime and food preferences become further evidence of their mental health disorder. In contrast, preferences are 'in order' when done by a person who is deemed to be normal; many 'normal' people make decisions multiple times daily about when, what, how and with whom to eat, without issue. Their preferences are seen as merely choices which - in the best-case scenario - are respected; and in the worst-case scenario are perceived as 'odd,' or 'annoying.' Ironically, because autistics prefer routinized rituals and unchanging food choices, their preferences are arguably 'in order' because they reflect the value that they too place on eating orders, albeit eating orders that are customized to each individual's experience as opposed to widely shared by society. That is, if provided with the food they want, in the way they want, their eating practices are very ordered, not in keeping with societal expectations, but in line with their own sense of what works best for them.

Treatments to alter autistic eating typically try to re-order the autistic in accordance with dominant eating orders. As with other psychiatric "treatments," ABA is an approach aimed at this outcome, one that is concerned more with 'recovery' (in this case eating what the parents decided the child should eat) than with treating the root causes (often sensory over- or under-stimulation). This version of recovery, as Schott and Langan (2024) note, casts the diagnosed "as individually responsible for ridding themselves of 'the disorder'" (p. 4) rather than acknowledging the role played by factors beyond their control (e.g., autistics' needs for routines, sensory sensitivities, food preferences, socially approved eating orders). It is simpler to force a child to eat food that has been spat out than to listen to, and accommodate, their unique needs. The pathologization of autistic eating provides a justification to steamroll over autistics' autonomy, similar to how those who have been given the label of eating disorder have their agency removed and "are acted *upon* with dehumanizing logics" (Schott & Langan, 2024, p. 4, emphasis in original).

Autistics feel strongly that medical professionals should see their feeding needs as intrinsic and not a choice, and that these behaviours should not be "pathologized or seen as an illness" (Kinnaird et al., 2019, p. 11). Rather, a disability-friendly approach is required, a more radical autistic scholarship, done by autistics, that starts from the perspective that we

do not "have a disorder." This orientation is in keeping with Schott and Langan's (2024) call for more "radical scholarship that resists prevalent notions of 'recovery' and expresses outrage in response to the systemic violence that is perpetuated by responses" (p. 9) to those who have been 'diagnosed' as eating disordered. I extend this call and express my outrage with respect to the systemic violence that is inflicted on autistics who have been framed as having an eating disorder.

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