



Using parent- and self-reports to evaluate eating disturbances in young girls with Autism Spectrum Disorder



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ARTICLE INFO

Keywords:

Autism
Eating disturbances
Assessment
Parent/child

ABSTRACT

Background: Eating Disturbances (ED) often occur in Autism Spectrum Disorder (ASD) but most previous studies have relied on parent-reported data about males with ASD. Few studies have collected data from younger girls with ASD using self-reports and parents' reports.

Aims: To compare self-reports and parents' reports of ED in a sample of 52 young girls with ASD, a standardised scale for ED was revised for use with younger girls with ASD.

Methods: Mothers of 52 girls with ASD aged from 6 to 17 years completed the Swedish Eating Assessment for Autism spectrum disorders (SWEAA) on their daughters; the girls also completed the SWEAA as a self-report.

Results: The prevalence of severe ED in the sample was low (about 11%). There were minimal significant differences between mothers' and daughters' SWEAA responses across most SWEAA subscales. Deletion of several of the original SWEAA items produced a scale that can be used as a self-report or a carer-report with young girls with ASD.

Conclusion: The clinical assessment of ED via self- or parent reports is suggested as a pathway to identify girls with ASD who also exhibit ED so that adequate treatment planning can be developed for them.

1. Introduction

1.1. Eating disturbances in Autism spectrum disorder

Young people with Autism Spectrum Disorder (ASD) exhibit difficulties in social communication and interaction, and in a range of possible behavioural symptom clusters related to the second of the two core diagnostic criteria for ASD: restricted and repetitive behaviour (RRB) patterns (APA, 2013). One of the ways that RRBs manifest themselves is via an insistence on sameness. When this occurs in relation to food selectivity and eating, it has been referred to as an “eating disturbance” (ED) which is “over-represented in ASD at all ages and all cognitive levels” (Rastam, 2008, p. 38). Vissoker et al. (2015) also noted that “A majority of children on the autistic spectrum suffer from some manifestation of food selectivity or picky eating” (p. 11). These observations have been consistent over time, with Kanner (1943) commenting on food-related disturbances in 6 of the 11 children with ASD he studied, suggesting that this is a well-established aspect of ASD. In addition, several reviews have confirmed the presence of eating disturbances in children and adolescents with ASD (Cermak et al., 2010; Ledford and Gast, 2006; Vissoker et al., 2015). Some issues for

further research have also been highlighted by those reviews.

1.2. Issues arising from previous research

First, in terms of information source about the child with ASD's ED, Cermak et al. (2010), in their review of 12 studies of eating disturbances in ASD children during the previous 25 years, found that data were collected from parental reports on their child's eating disturbances in 11 studies, while one study collected data from a laboratory-based study of observed eating preferences. Bandini et al. (2010) also developed an observational procedure for collecting data on ED, and others have used similarly objective methods (e.g., Hyman et al., 2012). However, in the most recent review update on this literature, Vissoker et al. (2015) noted that “most” studies of ED in ASD relied on parental reports, “which is inherently subject to bias” (p. 19). The continued use of parents as informants about their child's ED is demonstrated by two recent studies. Bicer and Alsaffar (2013) recruited 164 children with ASD aged 4–18 years and collected data on their ED from their parents; Beighley et al. (2013) also collected data from parents on their children's ED from a sample of 269 children with ASD (aged 2–18 years). However, in a break with this tradition of parent reports, Kuschner

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et al. (2015) collected self-reports from 65 high-functioning adolescents aged 12–28 years, using the Sensory Profile (Dunn, 1999) items from the taste/smell and touch subscales that referred to food selectivity. This use of self-reports from young people with ASD suggests that valid data regarding ED might be obtained from that source, although young children were not included in that study.

Second, gender of participants has also emerged as an issue for further research, in that most participants in previous studies were male, or gender was not reported. For example, Ledford and Gast (2006) found only two of the six studies they reviewed mentioned gender of the participant children (ranging from 73% to 83% male). Cermak et al. (2010) found that no distinction had been made between results from male or female participants with ASD in the 12 studies they reviewed. In fact, only one of the studies reviewed by Cermak et al. (2010) reported gender of their participants (the breakdown was 73% male). Vissoker et al. (2015) did not distinguish between male and female ED data in their review of the prevalence of ED in children with ASD. In Bicer and Alsaffar's (2013) study, the male:female ratio was 4:1; in the study reported by Beighley et al. (2013) 82% of participant children were male; Schreck et al.'s (2004) sample included only 10% females; and Kuschner et al.'s (2015) self-report of ED study did not report gender of participants.

Third, the definition of what constitutes ED varies across the literature and influences measurement processes. The eating disturbances examined in the studies mentioned above covered a wide range of food-related behaviours, including eating behaviour, concerns about the process of purchasing and preparing meals, social situations at meal-times and the environment surrounding meals, being able to detect personal hunger and/or satiety, and other similar behaviours surrounding food and eating (Karlsson et al., 2013). Vissoker et al. (2015) found that there was a lack of agreed definitions of what constituted eating disturbances and therefore little direct comparability of results across studies.

Fourth (and arising from the need to define ED), as hinted above, measurement of eating disturbances has been accomplished by a variety of scales. For example, in their study of 138 children with ASD and 298 children without ASD aged 5–12 years, Schreck et al. (2004) asked caregivers to complete the Children's Eating Behavior Inventory (Archer et al., 1991) and a researcher-made Food Preference Inventory. Results indicated that children with ASD exhibited significantly more feeding problems and ate a narrower range of foods than their non-ASD peers, although no gender-based comparisons were reported. Beighley et al. (2013) also had parents provide information about their child via the Autism Spectrum Disorder-Comorbidity for Children scale (Matson and Gonzales, 2007) and found that children with ASD had significantly more food selectivity than their non-ASD peers. Kuschner et al. (2015) used self-report data from the Sensory Profile (Dunn, 1999). This variability in scales used to measure ED in ASD makes direct comparison of results across studies difficult.

Finally, although early research on ED in ASD focussed upon the presence of intellectual disability as a correlate of eating disorders in ASD samples (e.g., Kinnell, 1985; O'Brian and Whitehouse, 1990), reviews of more recent studies have examined the association between ED and ASD in higher functioning young people (Vissoker et al., 2015). Whether the specific eating disturbances are related to food *per se*, intellectual disability, or represent an example of ASD-related insistence on sameness that encompasses eating and food, remains a matter of some conjecture but the current diagnostic criteria for ASD list "Extreme reaction to or rituals involving taste, smell, texture, or appearance of food or excessive food restrictions are common and may be a presenting feature of autism spectrum disorder" (APA, 2013, p. 54). The continued exploration of food disturbances independently of the confound of intellectual disability remains of relevance to the understanding of ASD and treatment planning for young people with ASD.

1.3. Aims of the study

Therefore, in response to the issues raised above from the previous literature, the current study was designed to (i) address the issue of source of information by comparing parents' ratings versus self-ratings of ED in a sample of children and adolescents with ASD; (ii) extend the previous literature on ED in ASD (that had been collected on predominantly male samples) by recruiting a sample consisting solely of females with ASD; (iii) collect data using a well-defined ED construct and instrument with multiple subscales so as to obtain a comprehensive picture of ED across several facets; and (iv) remove the possible confound of ED with intellectual disability by restricting the sample to females with ASD who are also high-functioning. Two secondary aims were to provide some basic comparisons with the previous data reported about the ED instrument used here, acknowledging the difference in ages across the current and past samples, and to provide some information regarding the psychometric status of the instrument used to collect information about ED.

2. Methods

2.1. Participants

The sample consisted of 52 girls (M age = 10.0yr, SD = 2.7yr, range = 6yr–17yr) with ASD and their mothers, all recruited from a local parent support group and ASD service organisations in Queensland, Australia, via an advertisement on the webpage of those organisations and word of mouth. As such, this was a community sample, with none of the participants being drawn directly from a clinical source such as a hospital, special school, or clinic. All these girls had received their original diagnosis of ASD based upon a 2-h clinical interview with their parents using the appropriate DSM-based diagnostic criteria for ASD, plus family history. These interviews were conducted by either a registered paediatrician or psychiatrist and were confirmed at the time by a suitably qualified and registered clinical psychologist with expertise in ASD. These original diagnoses were later confirmed by administration of the ADOS-2 (Lord et al., 2012) by a research-competent staff member during recruitment for this study. All the girls had originally received a Full Scale IQ above 70 on the WISC-IV, also confirmed by the WASI-II during recruitment; they were attending mainstream schools and were capable of self-care appropriate to their age, allowing them to be classified as high-functioning.

2.2. Instruments

2.2.1. The autism diagnostic observation schedule second edition (ADOS-2)

The ADOS-2 (Lord et al., 2012) is a highly recommended standardised diagnostic observation tool for ASD (Filipek et al., 1999; National Research Council, 2001). It presents a series of standardised interactive activities that focus upon social interactions, communication and repetitive behaviours, providing data for a diagnosis of ASD.

2.2.2. The wechsler abbreviated scale for intelligence (WASI-II)

The WASI-II contains four subtests with average reliability coefficients of between 0.92 and 0.96, and has strong validity with the WISC-IV when used with high-functioning people with ASD (Minshew et al., 2005). Results from the WASI-II provide an accurate estimate of intelligence that is useful for research screening purposes and produces results on two composite scales (Verbal Comprehension, Perceptual Reasoning), plus a Full Scale IQ based on those two composites. The Full Scale IQ was used as the measure of cognitive ability in this study.

2.2.3. The swedish eating assessment for Autism spectrum disorders (SWEAA)

The SWEAA was developed by Karlsson et al. (2013) on the basis of a "thorough literature review by Rastam (2008), combined with the

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