

Parent-reported feeding and swallowing difficulties of children with Autism Spectrum Disorders (aged 3 to 5 years) compared to typically developing peers: a South African study

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Abstract

Background: Research on aspects of neurodevelopment such as feeding and swallowing difficulties in children with Autism Spectrum Disorders (ASD) is limited in low and middle income countries such as South Africa.

Method: A descriptive comparative group design was used to investigate feeding and swallowing difficulties of young children with ASD in comparison to typically developing peers. The Brief Autism Mealtime Behavioural Inventory (BAMBI) was used.

Results: Findings indicated a significant difference in the severity of feeding and swallowing difficulties between the two groups. Difficulties such as food selectivity, sensory processing difficulties, oral-motor difficulties and symptoms of dysphagia were identified. The findings added to the existing global literature on feeding and swallowing difficulties in young children with ASD but provide a unique first perspective on these difficulties in South African children with ASD.

Conclusion: Findings also highlighted the use of the BAMBI as an adjunct clinical tool to encourage comprehensive parental report during feeding assessment in this population. Cultural adaptation of the BAMBI for future use in African countries should be considered. A better local understanding of the parental perspective on the multidimensional nature of the feeding and swallowing difficulties displayed by young children with ASD was obtained.

Keywords: Parent-reported feeding, swallowing difficulties, Autism Spectrum Disorders, South Africa.

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Introduction

Autism spectrum disorders (ASD) represent a range of complex neurodevelopmental disorders varying in severity that are characterized by a cluster of symptoms, including impairments in social interaction, communication, sensory integration difficulties and behaviour^{1,2,3}. Individuals with ASD demonstrate restricted, repetitive and stereotypical interests, activities and behaviours. Global research indicates that the disorder is typically first diagnosed in infancy and early childhood (as young as 18 months), and usually emerges before the age of three^{1,2}. Most research about ASD stems from high-income coun-

tries, but there have been quite a few studies in Africa, particularly in South Africa and Nigeria.

One such study by De Vries⁴ indicated that parents only became concerned for their child's behaviour at 22.5 months and that the diagnosis of ASD was on average made at 44.7 months. De Vries⁴ also states that a lack of research funding impacts on the development of assessment policies and guidelines in most African countries. As limited as diagnostic resources and interventions are in South Africa, they are far more abundant than in other African countries. As a result little is known about ASD and neuro-development, such as specific feeding behaviours and swallowing difficulties of children with ASD⁵, in low-and middle income countries. A dearth of research remains globally and in the African context on feeding difficulties in ASD^{6,7}.

Behavioural feeding difficulties and atypical eating is pervasive among children with ASD with prevalence as high

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as 46-89%^{6,7}. Such difficulties may pose a significant challenge during family mealtimes creating tense interactions between family members and increasing the burden of stress⁶. Limitations in previous global research studies include a dearth of research on feeding difficulties in ASD, restricted generalizability of findings due to small sample sizes as well as insufficient knowledge of comorbid medical conditions, such as eosinophilic esophagitis (EE)⁵. EE has an impact on the gut microbiome in children with ASD, which ultimately may have a greater impact on feeding than ASD itself⁵. An insufficient understanding of how the feeding behaviours of children with autism compare to the feeding behaviours of children without autism is an additional limitation⁵. Martins and colleagues⁸ noted that parents of children with ASD perceived a higher incidence of feeding difficulties compared to parents of typically developing children. These researchers thus encouraged the comparison of eating behaviour of children with ASD and typically developing (TD) children, since 25-45% of TD children also exhibit eating and feeding difficulties⁸.

The feeding problems associated with ASD include food selectivity, picky eating, oral-motor difficulties, obsessive eating patterns, inappropriate eating rate, food cravings, pica, restricted use of utensils and specific food presentation^{6,9,10}. Dysphagia may also be common in children with ASD, although more definitive information is needed regarding its manifestation in this population⁹. Secondary problems may include nutritional deficiencies, increased risk for illness, aspiration pneumonia, dehydration, airway obstruction, weight loss or obesity and significant health problems such as rickets with adverse effects on the quality of life^{11,12,13}.

From the preceding literature it is apparent that a dearth of studies on feeding and swallowing difficulties in young children with ASD exists in South Africa. Globally as well as in the multiracial and multicultural South African context, the need for further research on this topic was identified. The aforementioned consequences of feeding and swallowing problems, such as negative health sequelae and challenges in the home and social environments created added impetus for further research. One such a need was to investigate parental perception on feeding and swallowing difficulties in young children with ASD in comparison to their typically developing peers and it

is likely the first study of its kind in the South African context.

Method

Ethical clearance was obtained from the Research Ethics Committee at the University of Pretoria, South Africa.

Research design

A descriptive static-group comparison design¹⁴ was used to investigate the feeding and swallowing difficulties of **3:0 to 5:11** year old children with ASD in comparison with typically developing peers.

Participants and sampling

The group of children with ASD included 21 parents of children from varying cultural groupings in Gauteng, South Africa (aged **3:0 to 5:11** years) with a confirmed diagnosis of ASD. The TD group included 21 parents of typically developing peers (in the stated age range). The inclusion criteria for selecting this age range was due to the diagnosis and diagnostic application measures of ASD in children under the age of three years not being well established^{1,15}. ASD diagnostic status was confirmed by each child's treating physician or medical team.

Purposive sampling was used¹⁶. Telephone and e-mail contact were made with relevant societies representing children with ASD and preschools to access TD children, as well as the parents to be included in the study. A document including information regarding the study was firstly sent to the various societies/preschools via e-mail in order to obtain permission to contact the parents involved in each institution. Thereafter, an information brochure was sent to parents via e-mail, requesting their participation in the study. The purpose of the study was explained to both the societies/preschools and the parents. Lists of the parents' e-mail addresses were obtained from the various societies/preschools. Once these were obtained, it was possible for the researchers to send online informed consent documents and questionnaires to every parent on the list. It was necessary for the researchers to include contact information, information on the study and their credentials in the informed consent forms as this creates opportunities for e-mail interaction between researchers and participants.

The demographic information and characteristics for the two groups are presented in Table 1 and Table 2.

Table 1: Participant description typically developing children (n=21)

Participant characteristics	Frequency	%	
Age	<i>3:0-3:11</i>	8	38
	<i>4:0-4:11</i>	8	38
	<i>5:0-5:11</i>	3	14
	<i>Not indicated*</i>	2	10
Gender	<i>Male</i>	10	48
	<i>Female</i>	11	52
Other medical conditions	<i>None reported**</i>	20	95
Parental level of education	<i>Matric</i>	2	10
	<i>Diploma/Degree</i>	14	66
	<i>Post-graduate qualification</i>	5	24
Parental employment status	<i>Employed</i>	12	57
	<i>Unemployed</i>	1	5
	<i>Full time caregiver, i.e. stay-at-home parent</i>	8	38
Average monthly family income	<i><ZAR5000</i>	1	5
	<i>ZAR5000-10 000</i>	0	0
	<i>ZAR10 000-15 000</i>	3	14
	<i>ZAR15 000-20 000</i>	1	5
	<i>ZAR20 000-25 000</i>	3	14
	<i>>ZAR25 000</i>	12	57
	<i>Not indicated</i>	1	5
Cultural grouping/s of family	<i>Northern Sotho</i>	1	5
	<i>Southern Sotho</i>	1	5
	<i>English</i>	10	48
	<i>Afrikaans</i>	4	19
	<i>Swati</i>	1	5
	<i>English & Afrikaans</i>	3	14
	<i>Xhosa & Zulu</i>	1	5
Province	<i>Gauteng</i>	12	57
	<i>Mpumalanga</i>	5	24
	<i>North West</i>	2	10
	<i>Eastern Cape</i>	1	5

Table 2 Participant description children with ASD (n=21)

Participant characteristics	Frequency	%	
Age	<i>3:0-3:11</i>	9	43
	<i>4:0-4:11</i>	6	27
	<i>5:0-5:11</i>	5	24
	<i>Not indicated*</i>	1	5
Gender	<i>Male</i>	16	76
	<i>Female</i>	5	24
Diagnosis of ASD made by...	<i>Paediatric neurologist/ Developmental paediatrician</i>	15	71
	<i>Psychiatrist</i>	1	5
	<i>Team**</i>	5	24
Other medical conditions	<i>None</i>	16	75
	<i>Eczema</i>	1	5
	<i>Neurofibromatosis</i>	1	5
	<i>Heart conditions</i>	1	5
	<i>Food allergies/intolerances</i>	1	5
	<i>Ear infections</i>	1	5
Parental level of education	<i>Grade 10</i>	1	5
	<i>Matric</i>	9	43
	<i>Diploma/Degree</i>	6	29
	<i>Post-graduate qualification</i>	4	19
Parental employment status	<i>Employed</i>	9	43
	<i>Unemployed</i>	4	19
	<i>Full time caregiver, i.e. stay-at-home parent</i>	7	33
	<i>Not indicated</i>	1	5
Average monthly family income	<i><ZAR5000</i>	6	29
	<i>ZAR5000-10 000</i>	0	0
	<i>ZAR10 000-15 000</i>	0	0
	<i>ZAR15 000-20 000</i>	5	24
	<i>ZAR20 000-25 000</i>	3	14
	<i>>ZAR25 000</i>	3	14
	<i>Not indicated</i>	4	19
Cultural grouping/s of family	<i>Zulu</i>	4	19
	<i>Northern Sotho</i>	2	10
	<i>Southern Sotho</i>	5	24
	<i>English</i>	1	5
	<i>Afrikaans</i>	5	24
	<i>German & English</i>	1	5
	<i>English & Afrikaans</i>	2	10
	<i>Southern Sotho & Afrikaans</i>	1	5
Province	<i>Gauteng</i>	12	57
	<i>Mpumalanga</i>	4	19
	<i>Free State</i>	5	24
Demographic distribution	<i>Rural</i>	1	5
	<i>Semi-rural</i>	4	19
	<i>Urban</i>	16	76

*Although not indicated by two of the parents, the societies or pre-schools ensured that only parent with children in the specified age range (3:0-5:11) participated in the study.

**The team included a paediatric neurologist/developmental paediatrician, psychiatrist, psychologist, occupational therapist and speech-language therapist.

The characteristics of the children with ASD and the TD peers in terms of age and gender were mostly similar. Conversely, the males with ASD far outweighed the female cohort (16:5). Having more males present with ASD in a study is fairly common. However, the parental information for the two groups presented with some disparities regarding their education level, employment status and average monthly income as well as demographic distribution. The majority of parents (66%) from the TD

group had either a diploma or degree with only one of the parents being unemployed, whereas 29% of the parents from the ASD group had a diploma or degree and 4 parents (19%) were unemployed. This correlated with the monthly income of the parents as the group of parents from the TD group had a higher monthly income. Furthermore the demographic distribution was different as 76% of the group of ASD participants resided in urban areas whereas 95% of the TD group did.

Variables

Categorical variables such as age, gender and diagnostic status were included to ensure that the experimental and control groups came from similar backgrounds as to eliminate confounding variables. The quantitative variables that were examined in the BAMBI¹⁷ were measured on a Likert scale to obtain numerical data that fell on a continuum. As the BAMBI questionnaire was developed from a psychological and behavioural perspective, the

current study described the variables categorically (without changing the content of the BAMBI) to comprehensively investigate the feeding and swallowing difficulties in children with ASD. Hence, categorical variables measured with the BAMBI included the presence of oral-motor difficulties; the presence of obsessive eating patterns; sensory processing difficulties; the requirement of specific utensils, food presentation and symptoms of dysphagia. The variables investigated are presented in Table 3.

Table 3 Variables measured by the BAMBI

Measured variable	Questions on the BAMBI related to variable	Rationale for variable inclusion
Atypical feeding behaviour	Q1: My child cries or screams during mealtimes. Q3: My child remains seated at the table until his/her meal is finished. Q5: My child is aggressive during mealtimes (pushing/throwing utensils for food). Q6: My child displays self-injurious behaviour during mealtime (hitting self, biting self). Q7: My child is disruptive during mealtimes (pushing/throwing utensils for food).	Children with ASD exhibit strong behavioural responses when offered food they do not wish to consume such as getting up from their seats during a meal and throwing food. These behaviours are considered to be disruptive during mealtimes. Self-injurious behaviour is also characteristic of ASD.
Food selectivity and preferences	Q2: My child turns his/her head away from food. Q8: My child closes his/her mouth tightly when food is presented. Q10: My child is willing to try new foods. Q11: My child dislikes certain foods and won't eat them. Q13: My child prefers the same foods at every meal. Q15: My child accepts or prefers a variety of foods. Q17: My child prefers only sweet foods (sweets, sugary cereal). Q18: My child prefers to have foods prepared in a particular way (for example, fried foods, cold cereals, raw vegetables).	Food selectivity encompass food refusal and is manifested in behaviours such as turning the head away and mouth closure upon presentation of unwanted food. Picky eating is indicated when a child refuses to eat or even try a variety of foods or eats the same foods at every meal. Picky eating is linked to food selectivity.
Oral-motor difficulties	Q4: My child expels food that he/she has eaten. Q12: My child refuses to eat certain foods that require a lot of chewing	Children may expel food as a result of oral-motor difficulties. Chewing is one example of a complex oral-motor skill that if not adequately performed can contribute to feeding problems.
Sensory processing difficulties	Q4: My child expels food that he/she has eaten. Q12: My child refuses to eat certain foods that require a lot of chewing Q14: My child prefers "crunchy" foods (for example, snacks and crackers). Q18: My child prefers to have foods prepared in a particular way (for example, fried foods, cold cereals, raw vegetables).	Children with oral sensory difficulties may have low registration of food in the mouth and may expel it. The texture of food may be rejected by children with ASD due to sensory processing issues that may not support chewing of food. Preferences regarding textures of foods are linked to sensory processing deficits.
Dysphagia	Q4: My child expels food that he/she has eaten. Q12: My child refuses to eat certain foods that require a lot of chewing	Dysphagia can occur at various phases of swallowing, and the oral phase involves skills such as sucking and chewing.
Obsessive eating patterns	Q9: My child is flexible about mealtime routines (for example, times for meals, seating arrangements and place setting). Q16: My child prefers to have food served in a particular way.	Obsessive eating patterns may be related to the need for rigid routines in children with ASD.
Requirement of specific food presentation and utensils	Q16: My child prefers to have food served in a particular way.	The need for specific food presentation and use of familiar preferred utensils may also be linked to the need for rigid routines in children with ASD.

Materials

The validated Brief Autism Mealtime Behaviour Inventory (BAMBI) was selected for this study since it can be utilized by a variety of healthcare professionals^{17,18}. The BAMBI questionnaire consists of questions that elicit information about the child's behaviour and skills during mealtimes as well as the child's food preferences and acceptance. This questionnaire was accompanied by a self-developed background questionnaire to obtain relevant information regarding the demographics, socio-economic status and biographical information of the participants and their children. In addition, general information regarding a history of feeding and swallowing difficulties experienced before the age of three years was obtained. The two questionnaires were electronically linked to improve user friendliness in the parental survey.

Procedures

An online survey was conducted over a two month period. The electronic questionnaire was sent via e-mail to the research participants in a programme entitled Google Docs. Data recording was done automatically in the programme and the findings of the questionnaires were stored in Microsoft Excel 2010 format.

Data processing and analysis

Parental responses were arranged on a Likert scale to convert parental reports of feeding and swallowing difficulties into quantitative data. To obtain an indication of the feeding and swallowing difficulties, the BAMBI questionnaire (questions 15 to 32) was analysed. To analyse the BAMBI questionnaire a total score of the feeding and swallowing difficulties for each child was derived, totaling the sum of the Likert responses - bearing in mind that questions 17, 23, 24 and 29 were reverse-scored.

For each question, the response indicating the most severe feeding/swallowing problem correlated with a score of 5. The total score for questions 15 to 32 was calculated on Microsoft Excel 2010 which determined the general severity of the feeding and swallowing difficulties that

were reported. The higher the value of the total score, the greater the severity of the feeding and/or swallowing difficulties experienced by the child. After calculating the total score for each participant the composite scores were obtained for each variable as they related to individual participants. This entailed summing responses for questions measuring specific variables to obtain a severity score for each variable as they related to each participant. Hence, the composite scores for each variable, as well as the total scores, were converted into percentages using STATA: Data Analysis and Statistical Software 28 Version 11. These percentages represented the fraction of severity which each participant experienced for each variable, with 100 percent representing the most severe difficulty.

The means, medians, standard deviations and ranges for the experimental and control groups were determined. Normally distributed variables were analysed with the t-test ($p > 0.05$ = statistical significance).

The Wilcoxon rank-sum test was used to determine whether the differences between the median values for each group were statistically significant, thus enabling comparison of the atypical feeding behaviours in children with ASD and TD peers. Furthermore oral-motor difficulties, obsessive eating patterns, sensory processing difficulties, requirement of specific utensils and food presentation and symptoms of dysphagia were compared.

Reliability and Validity

Satisfactory reliability and validity was present by using the validated BAMBI questionnaire^{17,18}. The limitation of confounding variables facilitated external validity to the larger paediatric ASD and typically developing populations.

Findings

The parent reported feeding and swallowing difficulties of children with ASD were compared to those of TD peers by using the means, medians, standard deviations and ranges (minimum and maximum values) for the percentage scores of the variables under investigation. The findings are presented in Table 4.

Table 4 Comparative data: Young children with ASD and TD peers

Variable	Children with ASD (n=21)					Typically developing peers (n=21)					P-values*
	Mean	SD	Median	Min	Max	Mean	SD	Median	Min	Max	
Food selectivity and preferences	58	14	54	40	83	41	13	40	23	74	0.0002
Atypical feeding behaviours	44	17	40	24	84	28	6	28	20	36	0.0001
Oral-motor difficulties	48	24	50	20	100	30	13	30	20	60	0.0144
Sensory processing difficulties	54	15	55	20	75	39	13	35	20	65	0.0011
Obsessive eating patterns	57	16	53	33	100	45	19	40	20	80	0.0226
Specific utensils and food presentation	54	24	60	20	100	41	26	40	20	100	0.0529
Dysphagia	48	24	50	20	100	30	13	30	20	60	0.0144
TOTAL SCORE	53	12	50	39	77	38	10	36	24	62	

*Significance taken to be $p < 0.05$ for comparative variables on the Rank-Sum Test

The mean percentage score for the severity of total feeding and swallowing difficulties in children with ASD differed significantly from that of TD children ($p=0.0000$). This implies that the overall severity of feeding and swallowing difficulties differed between the two groups. The severity difference between the populations was statistically significant, with the ASD group scoring 15% higher. The mean percentage score for the severity of food selectivity and preferences in children with ASD also differed significantly from that of TD children ($p=0.0002$). The severity score in the ASD group was 17% higher than the TD group.

The differences between the median percentage scores of severity for atypical feeding behaviours, oral-motor difficulties, obsessive eating patterns, sensory processing difficulties and dysphagia between the two groups indicated a statistically significant difference in terms of these variables. However, there was not a significant difference ($p=0.0529$) with regard to the requirement of specific utensils and food presentation.

Participants in the group of children with ASD obtained higher median percentage scores for the severity of feeding and swallowing difficulties for all examined variables,

resulting in more severe problems regarding atypical feeding behaviours, oral-motor difficulties, obsessive eating patterns, sensory processing difficulties and symptoms of dysphagia.

The greatest differences in severity were found regarding oral-motor difficulties, sensory processing difficulties and symptoms of dysphagia. With the aforementioned variables, there was a difference of 20% between the two groups. The ASD group also displayed obsessive eating patterns that were 13% more severe than the TD group, which is statistically significant ($p=0.0226$). The variable of atypical feeding behaviours showed the smallest difference in severity between the two groups, however, it remains significant ($p=0.0001$).

Discussion

The findings of this South African study support the previously established notion, in global studies, that children with ASD exhibit more feeding difficulties than peers without the disorder^{5,7}. A novel finding that emerged was that participants in the group of children with ASD demonstrated swallowing difficulties not present in the TD group, a view which has received less attention in past literature⁹.

Food selectivity and preferences for children with ASD correlates with previous research findings indicating that food selectivity is more limiting for these children, than for typically developing peers¹⁹. Food selectivity can be due to extreme sensory modulation behaviours and sensory issues relating to smell, texture, colour and temperature of food¹⁹. Additional causes may be found in the ASD population's inflexibility and repetitive behaviour patterns²⁰. These sensory processing difficulties impacting negatively on feeding behaviour coincide with findings regarding children with ASD's preoccupation with sensory stimuli²⁰.

Although the BAMBI identified dysphagia as a problem for children with ASD, the specific type and description of dysphagia cannot be determined by parental report. The same applies for the impact of inadequate oral motor skills on feeding.

Another variable investigated was obsessive eating habits. Frequent occurrence of obsessive eating behaviour was identified in children with ASD and may be related to the restrictive, repetitive or stereotypical patterns of behaviour that is characteristic of this population⁷.

The findings regarding behavioural patterns during mealtimes such as crying or excessive screaming and disruptive behaviours are similar to findings from another research study⁷. This study found that children with ASD exhibit strong behavioural responses such as, pushing the plate or spoon away, and crying or turning their heads away when offered food they do not prefer or wish to consume⁷. Furthermore, children with ASD often required specific utensils and food presentation. This corresponds with findings of individuals with ASD experiencing severe difficulties with the use of feeding utensils from childhood into adulthood²².

The comparative findings of this context-specific study indicated significant feeding and swallowing difficulties in children with ASD. The specific nature of the feeding and swallowing difficulties are linked to problems such as food selectivity and preferences, sensory processing difficulties, oral-motor difficulties and symptoms of dysphagia, as well as obsessive eating patterns and atypical feeding behaviours as is evident from previous global studies.

Conclusion

The findings of this study add to the body of existing research, globally as well as in the South African context on feeding and swallowing difficulties in young children with

ASD. This context specific study provides a better understanding of the severity and wide ranging feeding and swallowing problems displayed in young children with ASD. The findings also highlight the use of the BAMBI¹⁷ as an adjunct clinical tool for healthcare professionals assessing feeding behaviours assessment in the ASD population. However, cultural adaptation of the BAMBI for future use in African countries should be considered since the cultural demographics of the participants were varied. Some of the questions used could be rephrased to become more culturally relevant when presented to participants. The BAMBI was received surprisingly well considering the linguistically diverse participant group and the fact that the tool was not normed for the South African context. The participants understood the majority of the English questions. In addition future research on a rural sample may be of further benefit since there may be differences in how parents view children's feeding and swallowing abilities. These opinions may be based on the availability and access to services as well as information shared with parents by healthcare professionals in rural settings.

The findings showed a significant difference in the severity and range of feeding and swallowing difficulties in children with ASD compared to TD peers. These problems highlighted the multidimensional nature of feeding and swallowing difficulties in children with ASD, though TD peers also displayed some feeding difficulties such as picky eating. The findings may enable healthcare professionals in Africa to better understand aspects of feeding and swallowing to address in evidence-based individualized assessment and intervention.

Due to the multidimensional nature of the feeding and swallowing problems an interdisciplinary team are best suited to address the full spectrum of feeding and swallowing difficulties in the paediatric ASD population²³. An interdisciplinary approach may contribute to decreased stress during mealtimes, safer swallowing and the development of functional skills required for oral feeding for all children with ASD. Interdisciplinary intervention may enable young children with ASD to engage more appropriately in mealtime activities of daily living. A further implication of the study was the need for parental education on the multidimensional aspects of feeding and swallowing difficulties young children with ASD experience that was emphasised by the findings.

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