

## RESEARCH ARTICLE

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# Investigating the impact of autistic children's feeding difficulties on caregivers

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## Abstract

**Aim:** The aim of this study was to investigate the influence of children's autism characteristics, sensory profiles and feeding difficulties on caregiver-reported impact at mealtimes.

**Background:** Caregivers of children (5–12 years) with a diagnosis of Autism Spectrum Disorder completed an online survey examining (a) demographic characteristics, (b) children's autism characteristics (Social Communication Questionnaire), (c) sensory profiles (Sensory Profile 2–short form), (d) feeding difficulties (Behavioural Paediatrics Feeding Assessment Scale, BPFAS) and (e) caregiver-reported impact of feeding difficulties (Feeding-Swallowing Impact Survey, FS-IS).

**Results:** Seventy-eight caregivers completed surveys for 80 children. Children with clinically significant feeding difficulties on the BPFAS ( $n = 55$ , 68.8%) had higher levels of caregiver-reported impact on daily activities, worry and feeding difficulties compared to children without clinically significant feeding difficulties (FS-IS;  $U = 257.000$ ,  $z = -4.471$ ,  $p < 0.01$ ). Spearman's rank correlation showed a statistically significant, moderate correlation between BPFAS total frequency score and FS-IS Daily activities score,  $r_s(98) = 0.56$ ,  $p < 0.01$ , indicating that as the frequency of feeding difficulties increased, the impact of these feeding difficulties on caregivers also increased. Using multiple regression, a model comprising of the three factors was statistically significant ( $F[1, 78] = 87.75$ ,  $p < 0.001$ , adj.  $R^2 = 0.52$ ), with children's frequency of feeding difficulties the strongest predictor of caregiver-reported impact with a moderate effect size ( $r = 0.49$ ).

**Conclusion:** Autistic children's feeding difficulties had a greater impact on caregivers than autism or sensory profiles, with the frequency of feeding difficulties and the caregiver impact of these feeding difficulties positively correlated. The findings demonstrate that efforts to understand and address feeding difficulties in autistic children must extend beyond the children to include their families.

## KEYWORDS

autism, caregivers, feeding difficulties, mealtimes, paediatrics

## 1 | INTRODUCTION

Feeding difficulties are common in autistic children and a frequent concern for their caregivers. Autistic children are five times more likely than non-autistic peers to have reported feeding concerns (Sharp et al., 2013) with an estimated prevalence of 46–89% (Ledford & Gast, 2006). The term *feeding difficulties* is an overarching term describing a range of difficulties related to food refusal, limited appetite, oral motor and/or swallowing difficulties (Milano et al., 2019). Pediatric Feeding Disorder (PFD) is an umbrella term proposed via expert consensus (Goday et al., 2019) and diagnoses based on a combination of clinical assessment and caregiver report (Dharmaraj et al., 2023). No direct clinical assessment was used in this study; thus, the term ‘feeding difficulties’ will be used throughout, acknowledging that many of these children may have PFD.

Existing research reports that autistic children's sensory profiles can contribute to their feeding difficulties (Boudjarane et al., 2017; Page et al., 2022; Smith et al., 2020) and that they are more likely to have a limited range of food (Bandini et al., 2010) with fewer fruits and vegetables (Bandini et al., 2010; Schreck et al., 2004) and higher carbohydrates (Schreck et al., 2004; Suarez & Crinion, 2015) in their diet. Furthermore, their reduced dietary variety, food neophobia and need for sameness has been positively correlated with the diagnostic criteria of restricted and repetitive patterns of behaviours, interests or activities (Enten-Vissoker, 2021; Hubbard et al., 2014; Suarez & Crinion, 2015). Yet, while the potential impact of feeding difficulties on autistic children's health and wellbeing is clear, the potential impact of these feeding difficulties on caregivers in relation to supporting their children at mealtimes is not well understood.

The importance of caregiver well-being in raising autistic children is well established, particularly given the additional stressors that many caregivers experience. For example, caregivers of autistic children have higher demands placed on them related to caring for their autistic children including attending additional health professional appointments (Davy et al., 2022; DePape & Lindsay, 2015). Davy et al. (2022) highlighted the impact on caregivers' quality of life, which influenced their own social participation levels for leisure, community access and employment. Yet caregiver wellbeing is often overlooked in the context of an autistic child's feeding difficulties despite the known impacts that feeding difficulties can have on family dynamics (Marshall et al., 2014; Meral & Fidan, 2015; Zhu & Dalby-Payne, 2019) and parental stress (McStay et al., 2014). Further understanding of autistic children's feeding and relationship to the caregiver impact of these feeding difficulties and resulting well-being is required.

The influence of autism severity on caregiver stress has been explored in the literature. McStay et al. (2014) used caregiver rating scales to explore parental stress in children aged 6–19 years of age. They found that caregiver stress was higher for children with higher levels of hyperactivity even when children's age, verbal ability and symptom severity were taken into consideration. However, more

### Key messages

- Autistic children can experience feeding difficulties that may impact not only their own health and wellbeing but also that of their caregiver-child dynamics at mealtimes.
- Variability in presentation of feeding difficulties for autistic children highlights the need for individualisation in assessment and therapy.
- Health professionals should consider providing support to caregivers as well as treating feeding difficulties in autistic children.
- Considerations at a policy level need to be made around supporting caregivers with managing stress and worry related to supporting their children with their feeding.
- Future co-designed research with the autistic community using a strengths-based approach will support more translatable research findings.

recent research exploring child predictors on caregiver strain and well-being has highlighted that it can be a combination of behaviours including hyperactivity as well as autism severity that can contribute to caregiver reported stress (Bradshaw et al., 2021). Such variability points to the need for a better understanding of autism severity and its relationship with caregivers and mealtimes.

The relationship between behaviour and sensory profiles on caregiver stress has been well researched with findings suggesting that autistic children's sensory processing differences can increase caregiver stress (Griffin et al., 2022; Kirby et al., 2019). There is also evidence that confirms children's sensory profiles can influence all areas of family daily life including mealtime routines (Bagby et al., 2012) demonstrating the need to gain a deeper understanding of the impact of autistic children's sensory profiles and feeding difficulties on caregiver stress.

Despite the complex underlying reasons behind feeding difficulties, few studies have explored the relative impact of children's autistic characteristics, sensory profiles and feeding difficulties on caregiver impact. The objective of this study was to evaluate the impact of three child-related factors (children's autism characteristics, sensory profiles and feeding difficulties) on caregivers' experiences of supporting their autistic children at mealtimes. The specific aims were to (a) examine the nature of feeding difficulties in autistic children, (b) examine the relationship between feeding difficulties and caregiver-reported feeding impact and (c) determine whether children's feeding difficulties predicted caregiver impact, over autism characteristics and sensory profiles. Based on clinical cases and impact studies exploring feeding difficulties in medically complex children, we hypothesised that the frequency of children's feeding difficulties would be a unique predictor of caregiver impact, and there would be a relationship between the frequency of children's reported feeding difficulties and caregiver impact.

## 2 | METHODS

### 2.1 | Design

An online survey design was used to address the research questions and was open for a period of 6 months (October 2021 to April 2022). The method and findings are reported in accordance with the 'Checklist for reporting results of internet e-surveys', CHERRIES (Eysenbach, 2004).

### 2.2 | Survey development

The online survey was designed and delivered in two sections comprising of tools that examined children's autism characteristics, sensory profiles and the nature of their feeding difficulties. Permission was obtained to include published and copyrighted tools.

#### 2.2.1 | Autism characteristics

The Social Communication Questionnaire (SCQ; Rutter, 2003) 'current form' was used to assess children's autism characteristics. It comprises of 40 yes/no questions relating to children's behaviour over the most recent 3-month period; it is suitable for children aged  $\geq 4$  years and has been shown to identify differences between non-autistic children and autistic children in a school-aged population cohort (Chandler et al., 2007). The SCQ yields a *total score* out of 39 points, with a cut-off of  $\geq 11$  associated with a diagnosis of Autism (Chandler et al., 2007). The SCQ *total raw score* was used as a measure of autism characteristics in the analysis.

#### 2.2.2 | Sensory profiles

The Sensory Profile 2–Short form (SSP-2; Dunn, 2014) was used to assess the children's sensory profiles includes 34 questions about children's behavioural responses to sensory stimuli (seeking, avoiding, sensitivity and registration) and has been used to identify differences in sensory subtypes in autistic children (Simpson et al., 2019). The SSP-2 *sensory processing total raw score* was used to account for sensory profiles in the analysis.

#### 2.2.3 | Feeding difficulties

The Behavioral Pediatric Feeding Assessment Scale (BPFAS; Crist & Napier-Phillips, 2001) was used to assess the frequency of feeding behaviours and the caregiver's feelings towards these. It comprises of 35 questions, has good test-retest reliability (Crist et al., 1994; Sanchez et al., 2015) and has demonstrated assessment efficacy in autistic children with feeding difficulties (Allen et al., 2015; Peverill et al., 2019; Zlomke et al., 2020). The test yields a problem and

frequency score with higher scores representing more problematic mealtime behaviours. Scores above 84 on the total frequency scale (TFS) indicate that a child presents with clinically significant feeding difficulties, and scores above 9 on the total problem score (TPS) indicate that these mealtime behaviours present a concern to the family (related to severity of the problem). Both scores were used in the analysis to explore the frequency of feeding difficulties (TFS) and level of caregiver concern present (TPS).

#### 2.2.4 | Feeding impact

The Feeding/Swallowing–Impact Survey (FS-IS; Lefton-Greif et al., 2014) was used to assess the impact of feeding on the caregiver and includes 18 items using a Likert scale across three subscales exploring quality-of-life (QoL) in relation to activities of feeding (six items), daily living (five items) and general worry (seven items) with lower scores suggesting a higher QoL. FS-IS has adequate validity in the assessment of QoL for caregivers of children with feeding difficulties (Lefton-Greif et al., 2014). The FS-IS *total score* was used in the analysis to explore the caregiver reported impact of having a child with feeding difficulties while the FS-IS *daily activities score* was used to understand the impact of increasing feeding difficulties on caregivers' daily lives. All three FS-IS subscales (feeding, daily living and general worry) were used to measure the caregiver impact against the frequency of feeding difficulties (as measured by the BPFAS).

### 2.3 | Participants

Study participants included 78 caregivers of 80 autistic children. Participants were initially recruited through purposeful sampling by contacting health professionals who work with autistic children. Providers were informed about the study and asked to invite families who fit the eligibility criteria. Inclusion criteria included caregivers of children aged 5–12 years with a diagnosis of Autism Spectrum Disorder from a medical professional using the criteria described in the Diagnostic Statistical Manual–5th edition, text revision (DSM-5 TR) (American Psychiatric Association, APA, 2022) or Diagnostic Statistical Manual–4th edition (DSM-IV) (APA, 2013). Participants were notified that the survey was open to all caregivers, including those who spoke English as their second language. However, it was outlined that the online survey was in English and an interpreter or translated copies of the survey were not available through the research team. Recruitment was extended by inviting caregivers of autistic children to participate via social media (e.g., Facebook autism parent groups) who were then required to confirm that their children had an Autism diagnosis in their consent forms. Participants were invited to ask questions prior to providing informed consent. A follow-up survey was sent after the study closed to gain additional demographic information because of an oversight with not including these questions in the original survey. Seventy-seven of 78 caregivers (98.72%) were mothers and approximately half (51.28%) aged between 30 and 39 years (Table 1).

**TABLE 1** Demographic characteristics: Caregivers of autistic children ( $n = 78$ ).

Characteristics	N (%)
Number of caregivers	78
Number of surveys completed	80
Gender	
Female	77 (98.72%)
Male	1 (1.25%)
Age	
20–29 years	7 (8.75%)
30–39 years	40 (51.28%)
40–49 years	29 (37.18%)
50–59 years	2 (2.50%)
Aboriginal and Torres Strait Islander Persons <sup>a</sup>	
Self-identified	1 (3.57%)
Heritage	2 (7.14%)
Origin of birth <sup>a</sup>	
Australia	28 (100.00%)
Languages spoken at home <sup>a</sup>	
English only	26 (92.86%)
More than one language (other than English)	2 (7.14%)
State/territory of residence <sup>a</sup>	
New South Wales	26 (92.85%)
Victoria	1 (3.57%)
South Australia	1 (3.57%)
Location of residence <sup>a</sup>	
Major city	13 (46.43%)
Regional and/or remote area	15 (53.57%)
Relationship to the child in the study	
Mother	75 (96.15%)
Father	1 (1.25%)
Caregiver (grandparent, foster carer)	2 (2.50%)
Number of children living at home	
1	11 (13.75%)
2	37 (47.44%)
3 or more	30 (37.50%)
Number of adults (over 18 years) living at home	
1	14 (17.50%)
2	59 (75.64%)
3 or more	5 (6.25%)
Level of education	
Up to high school	18 (22.50%)
Bachelor's degree	30 (37.50%)
Higher university qualifications	7 (8.97%)
Trade/TAFE	22 (28.21%)
Prefer not to say	1 (1.25%)
Employment status	
Employed	49 (62.82%)
Not currently employed	16 (20.00%)

**TABLE 1** (Continued)

Characteristics	N (%)
Not able to work	11 (13.75%)
Prefer not to say	2 (2.50%)
Household annual income	
\$0–\$45 000	13 (16.67%)
\$45 001–\$129 000	33 (41.25%)
\$120 001 and over	27 (33.75%)
Prefer not to say	5 (6.25%)

<sup>a</sup>This demographic information was collected via a follow-up survey with 28/80 respondents and a response rate of 35%.

**TABLE 2** Demographics of autistic children ( $n = 80$ ).

Characteristics	N (%)
Gender	
Female	11 (13.75%)
Male	69 (86.25%)
Age	
5–6 years old	23 (28.75%)
7–8 years old	22 (27.50%)
9–10 years old	22 (27.50%)
11–12 years old	13 (16.25%)
Schooling	
Mainstream	49 (61.25%)
Satellite class/support class in mainstream school	15 (18.75%)
Special needs school	11 (13.75%)
Home schooled	5 (6.25%)
Autism level of support <sup>a</sup>	
Level 1	8 (10.00%)
Level 2	54 (67.50%)
Level 3	17 (21.25%)
Not sure	1 (1.25%)
Diagnosed by	
Paediatrician	24 (30.00%)
Clinical psychologist	53 (66.25%)
Occupational therapist	1 (1.30%)
Child psychiatrist	2 (2.50%)

<sup>a</sup>Caregivers were asked to provide an overall rating based on the DSM5-TR criteria for severity levels.

Table 2 presents demographic information about the caregivers' children. The majority were male ( $n = 69$ , 86.25%), and two thirds ( $n = 54$ , 67.50%) were reported by caregivers to have overall Level 2 (medium supports) based on DSM5-TR severity level criteria. A large proportion of the sample (83.75%) reported co-occurring diagnoses, which two authors (VG and KW) classified according to the International Classification of Diseases 11th revision (ICD-11). Thirty-five per cent of the children had two co-occurring diagnoses in the ICD categories of Mental and Behavioural disorders (e.g., Anxiety and ADHD) and

Diseases of the nervous system (e.g., Epilepsy and Cerebral Palsy) with most of these diagnoses made by clinical psychologists as per caregiver report (66.25%). Fifty per cent of the cohort had a co-occurring diagnosis of ADHD, and 34 % had anxiety (see Tables S1 and S2).

## 2.4 | Analysis

Descriptive statistics were used to examine the demographic data and proportion of children who presented with clinically significant feeding difficulties as measured by the BPFAS total frequency score (cut of >84). Non-parametric testing was used, as data were not normally distributed. Mann Whitney-U tests were used to determine if the impact on families (measured by the FS-IS Total score) was greater in children with clinically feeding difficulties as compared those without feeding difficulties (as measured by the BPFAS TFS). The TFS was chosen to ensure that there was no overlap between the predictors of caregiver impact and feeding difficulties. A Spearman's correlation test, rather than Pearson's correlation, was used to examine the relationship between the discrete ordinal variables, frequency of feeding difficulties on the BPFAS and the impact of feeding difficulties on the family in the FS-IS. Multiple linear regression was used to examine whether the frequency of feeding difficulties (BPFAS) predicted the impact on families (FS-IS daily activities score), over other variables of autism characteristics (SCQ total raw score) and sensory profiles (SSP-2 total raw score). All assumptions were tested including homoscedasticity of residuals and approximate normality of residuals. Sample size was calculated a priori using G\*Power for multiple linear regression with  $\alpha = 0.05$ , power = 0.8 and three predictors (feeding difficulties, autism characteristics and sensory profiles). Tests were selected, conducted and reported according to conventions outlined in Laerd Statistics (Laerd Statistics, n.d.) using IBM SPSS Statistics.

## 3 | RESULTS

### 3.1 | Feeding characteristics of the children

The first aim of the study was to examine the nature of feeding difficulties in autistic children. The BPFAS *total frequency score* mean was

95.5 (SD = 18.3, range = 8–136), with 55 children who scored above 84, which was considered clinically significant (Ledford & Gast, 2006). Where caregivers reported their feelings regarding their children's feeding difficulties, a mean score of 15.89 (SD = 9.97, range = 0–31) using the BPFAS *total problem score* was observed. For the TPS, 57 children (68.75%) achieved a score above 9, which is indicative of clinically significant feeding difficulties (Ledford & Gast, 2006). A list of the caregiver reported BPFAS highest and lowest frequency feeding behaviours can be found in the [supporting information](#).

### 3.2 | Feeding difficulties impact on families

The second aim of the study was to examine the relationship between children's feeding difficulties and the impact of these feeding difficulties on their families. Medians (range) for each FS-IS subscale for children with and without clinically significant feeding difficulties are listed in Table 3. At a group level, the impact of children's feeding difficulties on caregivers (FS-IS *total score*) was found to be significantly higher for children who met the cut-off for clinically significant feeding difficulties than for children who did not (BPFAS TFS  $U = 257.000$ ,  $z = -4.471$ ,  $p < 0.001$ ), with a moderate effect size ( $r = 0.50$ ). The FS-IS subtests of worry ( $r = 0.50$ ,  $p < 0.001$ ), feeding difficulties ( $r = 0.43$ ,  $p < 0.001$ ) and total score ( $r = 0.50$ ,  $p < 0.001$ ) were all observed to have a moderate to large effect size between the two groups (clinically and not clinically significant feeding difficulties). However, the daily activities' subtest was slightly lower ( $r = 0.34$ ,  $p = 0.02$ ) despite all the subtests showing statistical significance ( $p < 0.05$ ).

Children's frequency of feeding difficulties (BPFAS-TFS) and the impact of feeding difficulties on the family (FS-IS scores) were correlated. Specifically, analysis of each FS-IS subtest revealed a moderate positive correlation between BPFAS TFS and FS-IS daily activities score ( $r = 0.56$ ,  $p = 0.02$ ), worry ( $r = 0.68$ ,  $p < 0.001$ ) and feeding difficulties ( $r = 0.62$ ,  $p < 0.001$ ). However, the FS-IS total score ( $r = 0.73$ ,  $p < 0.001$ ) indicated a high positive correlation with the BPFAS-TFS score. All correlations were statistically significant ( $p < 0.01$ ). Preliminary analysis showed the correlation between the FS-IS daily activities score and BPFAS-TFS scores to be in a non-linear monotonic relationship (i.e., both variables increased but at different rates) as assessed by visual inspection of a scatterplot. There was a

statistically significant, moderate correlation between BPFAS-TFS and FS-IS Daily activities score,  $r_s(98) = 0.56$ ,  $p < 0.01$ .

### 3.3 | Predicting the impact of feeding difficulties on families

The third aim of the study was to determine whether children's level of feeding difficulties predicted the impact on their families, over and above autism characteristics and sensory profiles. Multiple linear regression compared the dependent variable (FS-IS *total scores*) against the independent variables of feeding difficulties (BPFAS *total frequency raw scores*), autism characteristics (SCQ-*current form raw scores*) and sensory profiles (SSP-2-*short form raw scores*) to determine the extent that each individual factor accounted for the impact on families. In the model, frequency of feeding difficulties (BPFAS-TFS) was the strongest predictor of impact on daily activities (FS-IS score) ( $F[1, 78] = 87.75$ ,  $p < 0.001$ , adj.  $R^2 = 0.52$  (Laerd Statistics, n.d.)).

## 4 | DISCUSSION

Feeding difficulties have a substantial impact on the health and well-being of autistic children and their caregivers. This study explored the complex interplay of autistic children's feeding difficulties, sensory profiles and autism characteristics on caregiver impact. Caregivers' results demonstrated that their children's frequency of feeding behaviours impacted both their daily lives and level of worry. This caregiver impact was higher for autistic children with clinically significant feeding difficulties compared to autistic children without clinically significant feeding difficulties. Furthermore, when feeding difficulties increased in autistic children, the impact on these feeding difficulties on caregivers increased as well. Autistic children's feeding difficulties were a unique predictor of caregiver impact over, and above other factors tested (Table 4).

When exploring the nature of feeding difficulties in our cohort of autistic children, we found that the proportion of children who experienced significant feeding difficulties (69%) was similar to those reported in previous studies (Adams et al., 2021; Kang et al., 2021). However, despite this high frequency of feeding difficulties in autistic children, it should be noted that methodological rigor varied across

**TABLE 3** Scores for Feeding/Swallowing Impact Survey (FS-IS) subscales for children with and without clinically significant feeding difficulties.

FS-IS subscale	Not clinically significant ( $n = 25$ ) Median (range)	Clinically significant ( $n = 55$ ) Median (range)	$U$	$z$	$p$	$r$
Daily activities	13 (4, 25)	17 (5, 25)	394.50	-3.05	0.02*	0.34
Worry	17 (7, 26)	25 (7, 35)	258.50	-4.46	<0.001*	0.50
Feeding difficulties	9 (0, 17)	14 (2, 28)	314.00	-3.89	<0.001*	0.43
Total score	39 (14, 57)	56 (19, 83)	257.00	-4.47	<0.001*	0.50

\* $p < 0.05$ .



**TABLE 4** Linear regression examining the predictors on family impact.

Predictor	B	95% CI for $\beta$		SE $\beta$	$\beta$	$R^2$	$\Delta R^2$
		LL	UL				
Model						0.54	0.52
Constant	−0.17	−1.15	0.82	0.50			
BPFAS TFS	0.04	0.03	0.04	0.00	0.74*		
SSP	−0.00	−0.02	0.04	0.00	−0.04		
SCQ SP	−0.01	−0.03	0.01	0.01	−0.09		

Abbreviations: BPFAS TFS, BPFAS total score; SCQ, Social Communication Questionnaire 'current form'; SSP, Sensory Profile 2–Short form, sensory processing score.

\* $p < 0.001$ .

these studies (Sharp et al., 2013). Caregivers reported mealtime behaviours such as food negotiation, extended mealtimes and additional meal offerings upon food refusal along with a predominantly carbohydrate-based diet, which have all been previously described in other studies exploring feeding difficulties in autistic children (Ausderau & Juarez, 2013; Curtiss & Ebata, 2019; Marshall et al., 2014; Sharp et al., 2013). The findings demonstrate that autistic children may experience substantial feeding difficulties that can impact not only their own health and wellbeing but also that of the caregiver-child mealtimes dynamics.

When examining the relationship between feeding difficulties in autistic children and the impact on families, our findings were consistent with those of Şahan et al. (2021) in that caregiver worry was higher for autistic children with clinically significant feeding difficulties compared with autistic children without clinically significant feeding difficulties. When the level of feeding difficulties increased, the impact of feeding difficulties on the family on their daily lives also increased. This aligns with current clinical understanding about the greater challenges for families when an autistic child presents with more than one feeding difficulty (such as chewing difficulties and nutritional concerns, swallowing difficulties and mealtime refusal) with resulting higher complexities around support and bigger impact of feeding difficulties on caregivers. These results extend research already published in the field exploring the importance of clinicians addressing caregiver concerns (Bonsall et al., 2021) because it is impacting not only their autistic children but also the families' lives. Validating caregiver level of worry and understanding impact is crucial to enable a broader focus that is not just assessing feeding skills in autistic children. These quantitative findings build on qualitative work (Rogers et al., 2012) highlighting the impact of feeding difficulties on families and emphasis the need to work more collaboratively with autistic children and their caregivers in relation to feeding difficulties and mealtimes.

The third aim of the study was to determine the extent to which each factor (feeding difficulties, autism characteristics and sensory profiles) accounted for the impact of feeding difficulties on caregivers. Consistent with this study's hypothesis, frequency of feeding difficulties in our cohort was a unique predictor of caregiver impact, over other predictors such as autism characteristics and sensory profiles. This was a surprising result, given the expansive body of literature describing the relationship between sensory processing and parental

stress (Enea & Rusu, 2020; Page et al., 2022). These results are, however, consistent with the work done by Thullen and Bonsall (2017) who explored the impact of parenting stress with feeding challenges in 113 caregivers of autistic children aged 5–14 years. They found that while food selectivity was high, it was the mealtime behaviours that added the highest level of stress around mealtimes. Our study adds further information around mealtime behaviours as a unique predictor of caregiver stress but suggests that further research is warranted.

Our findings are also consistent with the broader literature (Page et al., 2022) that indicates that the level of autism characteristics (measured on the SCQ and commonly referred to as severity) is not associated with autistic children's feeding difficulties. Therefore, practitioners, and those who provide funding for supports, should avoid making assumptions regarding the likely needs of children and their families based on the children's autism characteristics. Our study adds further weight to the need for health professionals working in paediatric feeding to consider the factors behind mealtime stressors. This includes exploring the impact of co-occurring diagnoses of ADHD and anxiety (both highly represented in this sample) as well as exploring these influences on mealtime refusals with clinical psychologists and children's sensory needs with occupational therapists. The variability of different factors highlights the need for individualised assessment and therapy across all aspects of daily life cares for autistic children and their caregivers.

## 4.1 | Limitations

The findings of this study must be considered with respect to several limitations. First, while the use of an online survey was effective in reaching the target sample of 80 autistic children across geographical areas, it was not feasible with study constraints to contact caregivers for documentation to clarify autism levels or confirm diagnoses. Asking caregivers to provide diagnostic reports could be considered in future studies, however, was considered too burdensome on caregivers in this current study. Some of the demographic information about participants' race/ethnicity was also missing due to a survey error. A sample size of 80 was calculated apriori using G\*Power for multiple linear regression with  $\alpha = 0.05$ , power = 0.8 and three

predictors (feeding difficulties, autism characteristics and sensory profiles); however, exploring a bigger sample size would be useful to understand different cultural and demographical influences. Additionally, the geographical region was heavily weighted to the state where the first author resided in and not evenly distributed across all states of the country.

Another limitation was that data collection relied on caregiver report rather than direct assessment, which may have biased the results; however, direct assessment was not possible in an online survey. While the study was open to all caregivers of autistic children regardless of whether their child had feeding difficulties, it is acknowledged that caregivers were more likely to participate in this study if they were worried about their children's feeding. Therefore, frequency of feeding difficulties may be over-represented and not a true representation of the whole autistic community.

A strength of this study was the inclusion of reliable and valid caregiver-reported tools. We acknowledge that there was some conceptual overlap between the BPFAS and FS-IS tools, but the correlation between the TFS and FS-IS Daily Activity scores was found to be moderate, which would not have violated assumptions in our final regression model. While the Short Sensory Profile-2 (SSP-2) was used to explore the relationship of sensory profiles, the decision around selecting a screener as opposed to the Sensory Profile-2 was based on the need to reduce caregiver burden in what was a comprehensive one-hour survey.

## 4.2 | Implications and future directions

Our study highlights the impact of autistic children's feeding difficulties on their families. This is the first study to identify the unique contribution that autistic children's feeding difficulties make on caregiver impact over and above autism characteristics and sensory profiles. While the findings can immediately inform clinical practice by encouraging clinicians to begin the conversation with caregivers about how their children's feeding difficulties are impacting the family, future research can guide the development of new and desirable supports. First, study replication exploring the inter-play of the relationship between sensory profiles and feeding skills will deepen the research knowledge around autistic children's feeding and caregiver impact. However, in considering future research directions, consideration must be given not just to what is examined and explored but how the research is conducted. Working collaboratively with autistic caregivers as well as non-autistic caregivers will help health professionals explore how best to support caregivers and their autistic children.

Importantly, caregivers typically reported on their children's feeding difficulties, and while this acknowledges their real-life experiences, recent evidence from the autistic community encourages us to consider that these differences exist because of the challenges of living in a world that favours neurotypical/non-autistic feeding patterns. It is hoped that future research can work closely with the autistic community in bridging the gap around these differences to create more inclusive support.

## 5 | CONCLUSION

This study demonstrated that caregiver worry was higher for autistic children with clinically significant difficulties across the primary school aged group. More so, as the feeding difficulties increased in children, the impact of these difficulties on caregivers increased as well. Autistic children's feeding difficulties were a unique predictor of caregiver impact over and above autism characteristics and sensory profiles. These findings help inform health professionals of the importance of exploring the caregiver impact of their children's feeding difficulties rather than only assessing feeding impairment in autistic children and supporting caregivers in seeking additional support as needed. At a broader policy level, considerations need to be made around supporting caregiver level of worry with autistic children who present with feeding difficulties. Future research using a strength-based co-designed approach with the autistic community will ensure research findings are in line with best practice with supporting autistic children and their families.

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## CONFLICTS OF INTEREST STATEMENT

The authors, A/Prof David Trembath, A/Prof Kelly Weir and Dr Jeanne Marshall, all receive a salary from their affiliated institutions. Valerie Gent is a master's candidate completing this study under the Master of Medical Research postgraduate degree at Griffith University.

## DATA AVAILABILITY STATEMENT

De-identifiable data will be made available upon reasonable request to the corresponding author.

## ETHICS STATEMENT

Ethical approval for this study was obtained from the Griffith University Human Research Ethics Committee (GU HREC Project 2021/595).

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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