# TRANS-ADAPTATION AND VALIDATION OF BRIEF AUTISM MEALTIME BEHAVIOR INVENTORY IN TELUGU (BAMBI-T)

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A Dissertation Submitted in Part Fulfilment of Degree of

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University of Mysore, Mysuru



# ALL INDIA INSTITUTE OF SPEECH AND HEARING

# MANASAGANGOTHRI, MYSURU-570006

JULY, 2024

# CERTIFICATE

# This is to certify that this dissertation entitled "TRANS-ADAPTATION AND VALIDATION OF BRIEF AUTISM MEALTIME BEHAVIOR INVENTORY IN TELUGU (BAMBI-

**T**)" is a bonafide work submitted in part fulfilment for the degree of Master of Science (Speech-language Pathology) of the student Registration Number P01II22S123032. This has been carried out under the guidance of a faculty member of this institute and has not been submitted earlier to any other university for an award of any other diploma or degree.

Mysuru July 2024 Dr. M. Pushpavathi Director All India Institute of Speech and Hearing Manasagangothri, Mysuru -570006

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Mysuru July 2024 Guide Dr. Swapna N. Professor of Speech Pathology Center for Swallowing Disorders All India Institute of Speech and Hearing Manasagangothri, Mysuru -570006

## **DECLARATION**

This is to certify that this dissertation entitled "TRANS-ADAPTATION AND VALIDATION OF BRIEF AUTISM MEALTIME BEHAVIOR INVENTORY IN TELUGU (BAMBI-T)" is the result of my study under the guidance of Dr. Swapna N, Professor of Speech Pathology, Center for Swallowing Disorders, All India Institute of Speech and Hearing, Mysuru and has not been submitted earlier to any other University for an award of any other Diploma or Degree.

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#### **CHAPTER I**

#### **INTRODUCTION**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by restricted repetitive patterns of behaviour or interests and difficulties with social communication (American Psychiatric Association [APA], 2015. This disorder is influenced by both environmental factors and genetic factors affecting brain development. Neuropathological studies also revealed differences in cerebellar architecture and connectivity, limbic system abnormalities, and frontal and temporal lobe cortical alterations, along with other subtle malformations (Johnson et al., 2007). Neocortical architecture revealed focal disruption of cortical laminar architecture, suggesting problems with cortical layer formation and neuronal differentiation (Rubies et al., 2014).

There have been recent concerns about the increased prevalence of ASD. The prevalence of ASD is reported to be 1 in 36 children aged 8 years in the year 2020 (Maenner et al., 2021). According to a recent systematic review, in South Asian countries, the percentage prevalence rate of ASD in children aged 0–17 ranges from 0.09% to 1.07% (Baxter et al., 2015). Across five states of India, the prevalence of ASD was estimated to be 1 in 125 and 1 in 80 children between the ages of 2-6 and 6-9 years, respectively (Arora et al., 2018). In a study by Chauhan et al. (2019), ASD's pooled percentage prevalence was found to be 0.11 [95% confidence interval (CI) 0.01–0.20] in children aged 1–18 years in the rural setting and 0.09 (95% CI 0.02–0.16) in children aged 0–15 years in four studies conducted in the urban setting in Chandigarh, India (Arora et al., 2018).

ASD primarily affects two main areas: social communication and restricted repetitive and/ or sensory behaviours or interests. Social communication deficiencies associated with this disorder can manifest in various ways, including issues with verbal and nonverbal social interactional skills to take issues with social reciprocity and joint attention. Stereotyped, repetitive speech and physical movements, rigid constancy in following routines, narrow interests, and hypersensitivity and/or hyposensitivity to sensory input are indications of restricted, concurrent behaviours and interests that are seen in individuals with ASD.

Feeding and eating difficulties are the other common problems that affect individuals with autism who are of any age or cognitive ability (Rastam, 2008; Vissoker et al., 2015). It is well known that typically developing (TD) children, especially at preschool age, show an attitude of preference or rejection towards some foods; in such cases, children are referred to as "picky eaters". According to Kondekar et al. (2020), eating issues, including food refusals, specific texture preferences, and sluggish feeding, affect up to 25–35% of children who are typically developing. According to Carruth and Skinner (2000), this behaviour declines around the age of 6 years, as the children get more opportunities to eat outside the family context and as they are exposed to a greater variety of foods that promote the extinction of dietary restrictions. In individuals with autism, food selectivity may be present at a very early age and may be persistent during the life course. In comparison to typically developing children, those with ASD experience significantly greater feeding difficulties that include picky eating, limited independent feeding, need for increased feeding times, and a highly restrictive food repertoire (Adams et al., 2022).

Several other studies have also shown that children with ASD experience significantly more feeding problems than TD children (Cherif et al., 2018; Malhi et

al., 2017; Seiverling et al., 2018; Sharp et al., 2013). The estimated prevalence of feeding disorders in children with ASD varies from 30% to 60% (Marí-Bauset, Zazpe, Mari-Sanchis, LlopisGonzález, & Morales-Suárez-Varela, 2014; Noor Safiza & LeCouteur, 2015). According to Mayes and Zickgraf (2019), children with ASD (70.4%) exhibit atypical eating behaviours (such as food preferences being limited and having preferences for brand-specific) significantly more frequently when compared to children with other disorders (13.1%) and also in comparison with children in the general population (4.8%). Some of the recent studies also report a significantly greater percentage of children with ASD who exhibit feeding issues. For example, 80% of children with ASD may experience issues with their feeding behaviours (Castro et al., 2019). Up to 90% of children with ASD exhibit disruptive mealtime behaviour and problems related to food selectivity (Zlomke et al., 2020).

Three types of feeding problems in ASD children have been recognised, which include disruptive eating behaviours, food refusal, and selective eating (Cermak et al., 2010; Rogers et al., 2012; Schreck et al., 2004; Smith & Williams, 2004). As a result, they can only eat a certain type of food, show signs of food neophobia (resistance to eating unknown food), refuse food, have limited food textures, have unusual food preferences (like certain food colours, shapes, textures, appearances, or arrangements on the plate), and insist on using standard dishes and utensils. Several terms are being used in the literature to indicate the feeding problems seen in ASD, such as picky eating, fussy eating, food neophobia, restricted dietary variety, food refusal, food selectivity, and mealtime behaviour problems – terms that might cover several aspects, in addition to some of those previously referred to. Frequently found terms are 'limited food variety' and 'food selectivity' (Ledford & Gast, 2006; MaríBauset et al., 2014; Provost, Crowe, Osbourn, McClain, & Skipper, 2010). 'Food selectivity' is often

defined as the consumption of a limited range of food. Some other reports refer to terms such as 'food refusal', which refers to the rejection of food based on food groups, leading to, for example, the low consumption of fruit and vegetables (Sharp et al., 2013). Other mealtime behaviour problems such as food neophobia, restricted mealtime routines, tantrums, spitting food out, or vomiting (Ledford & Gast, 2006; Provost et al., 2010; Stough, Gillette, Roberts, Jorgensen, & Patton, 2015) have been reported. In addition, they have poor social behaviour at mealtimes, strange posturing during meals, oral motor issues, and a tendency toward obesity (Ziviani & Dodrill, 2014). They frequently exhibit sensory oversensitivity, oral defensiveness, and tactile defensiveness in the mouth, which results in nutritional selectivity (Baranek et al., 2007; Lane et al., 2010; Tomchek & Dunn, 2007; Williams et al., 2000).

A study by Varma et al. (2023) explored the early feeding patterns, including the feeding patterns of sucking during the first year of life of typically developing young children and children with ASD using the Brief Assessment of Mealtime Behaviour in Children scale (BAMBIC; Hendy et al., 2013). BAMBIC is a tool validated to make it applicable across various diagnostic conditions ASD, attentiondeficit/hyperactivity disorder (ADHD), sensory processing disorders, or other developmental delays. The results revealed that compared to typically developing children, there were notable variations in the early food habits of children with ASD. 64 % of children with ASD exhibited deregulated, forceful breastfeeding, with no awareness of when they should stop. Of these, 52% were breastfed for longer than 40 minutes each time. After the age of two years, 68% of mothers continued to breastfeed.

As per Mayes et al. (2018), there appears to be a possible correlation between eating problems and neurodevelopmental conditions like autism, though this correlation is unclear. Various factors have been claimed as explanations for the frequent occurrence of difficulties with feeding in individuals with ASD (Vissoker et al., 2015), which include difficulties in self-regulation, sensory issues, and social communication deficiencies (Gomez et al., 2005). Other factors include oromotor delay or food characteristics (texture, temperature) (Cermak, Curtin, & Bandini, 2010; Ledford & Gast, 2006; Marí-Bauset et al., 2014; Sharp et al., 2013). These factors are observed from early on in life and continue to exist. They have an impact on the feeding behaviours of ASD children from infancy to adolescence (Margari et al., 2020).

Because physical growth and neurodevelopment are most important during the critical years of infancy and early childhood, eating habits are a serious concern that may have long-term consequences if not properly managed at the appropriate time. Feeding problems, particularly 'food selectivity', might be related to anthropometric deviations and nutritional deficits as a consequence (Noor Safiza & LeCouteur, 2015; Sharp et al., 2013). Thus, healthcare professionals should be aware of these feeding-related issues in ASD and include the assessment of feeding problems in their clinical practice. Moreover, distinctive feeding patterns during infancy could potentially serve as indicators for early identification of ASD.

Several tools have been developed to assess feeding issues in this population, including observation and completed questionnaires for caregivers/parents (Matson & Fodstad, 2009). Most studies have relied on the latter to measure their feeding behaviours. The questionnaires are widely used since they are less time-consuming, can be administered irrespective of settings, are administered even by untrained personnel, and enable the identification of appropriate management strategies. Various feeding questionnaires have been developed to determine problems in feeding and mealtime behaviours in children with neurodevelopmental disorders, such as the Screening Tool for Feeding Problems (STEP; Matson & Kuhnn, 2001); Behavioural Paediatrics Feeding Assessment Scale (BPFAS; Crist & Napier-Phillips, 2001); The Swedish Eating Assessment (SWEAA, Karlsson et al. (2013); Aut-Eat Questionnaire (AEQ, GFal et al., 2021); Parent Mealtime Action Scale (PMAS-R; Hendy et al., (2016). Most of these tools have been developed for children with other neurodevelopmental disorders and have been validated for children with ASD.

One of the tools developed and used specifically for children with ASD is The Brief Autism Mealtime Behaviour Inventory (BAMBI). It is also a widely used feeding questionnaire for children with ASD in clinical and research studies. Lukens and Linscheid (2008) designed BAMBI as the first standardised informant report measure to capture mealtime and feeding behaviours explicitly in children with ASD. According to Seiverling et al. (2010), this tool was found to be a promising psychometric assessment of feeding functions in children with ASD.

This questionnaire includes a wide range of problematic behaviours that are frequently seen in this population and can be used in clinical practice to diagnose feeding problems in children with ASD quickly and accurately. In the original questionnaire, twenty items were divided into three domains: oral defensiveness, tactile defensiveness, sensory oversensitivity in the mouth, and nutritional selectivity (Baranek et al., 2007; Lane et al., 2010; Tomchek & Dunn, 2007; Williams et al., 2000). However, the authors drew attention to its shortcomings and modified it after six years. The revision comprised 18 items and rated the frequency of specific behaviours using a Likert scale (1 = Never, 2= rarely, 3= occasionally, 4= Often and 5 =Almost Every Meal). The scale yields a total score, as well as scores on three domains. Items 10, 11, 13, 14, 15, 16, 17, and 18 in the restricted variety factor measure the child's openness to experimenting with new foods and foods that differ in preparation, texture, and type. Five factors make up the food denial factor (items 1, 2, 4, 7, and 8), which describes the problematic behaviours that are shown when a kid rejects food that has been offered to them. The characteristic component of ASD (items 3, 5, 6, 9, and 12) includes elements that indicate the behavioural traits of ASD, such as self-aggressive and stereotyped actions during meals. The questionnaire is completed by the parents/caregivers (Castro et al., 2019). Reverse-scoring was observed for item numbers 3, 9, 10, and 15 to obtain a frequency score, which is calculated as the sum of the Likert responses. A high rating on the scale indicates that the particular behaviour described by each item is a prominent and persistent issue in the child's mealtime routines, potentially signalling significant challenges in feeding and mealtime behaviours.

## 1.1 Need for the study

A look into the literature revealed that a high percentage of children with ASD exhibit feeding problems. However, some of these problems may not be evident during the clinical feeding evaluation. It is of great importance to understand the nature of the feeding problems through a thorough assessment of this population; this includes being able to precisely determine, explain, and diagnose feeding problems. Comprehensive questionnaires must be used to profile all possible feeding-related issues in these children. Though there are a few parent and/or caregiver-reported tools in order to understand the problems associated with feeding in children with ASD, BAMBI is a widely used tool with good psychometric properties. The BAMBI questionnaire is a helpful tool for analysing feeding-related problems in children with ASD.

Besides the original version, BAMBI (Lukens et al., 2007) was translated and validated into Italian (Lamboglia et al., 2023), Thai (Chunsuwan et al., 2021), Vietnamese (Huong et al., 2021), Malay (Nor et al., 2019), Brazilian Portuguese (Castro et al., 2019) and into Malayalam (Tomson, 2023), which is an Indian Language. This indicates that the BAMBI is sensitive to the feeding issues in children with ASD. For this reason, Speech-Language Pathologists (SLPs) prefer to use the well-researched BAMBI questionnaire rather than other questionnaires when evaluating issues related to feeding.

BAMBI requires parents to participate actively and to carefully observe their child over time in natural settings during mealtimes. BAMBI is a tool completed by parents/caregivers. For this reason, the parents' native language is required for this questionnaire. Thus, there is a need for translation, adaptation, and validation in different languages. In the Indian context, BAMBI has been translated into Malayalam (Tomson, 2023). This study aimed to translate and validate the same into Telugu. Translating the content into any language involves adapting it to account for linguistic and cultural variances. The validation would allow for the integration of a structured feeding assessment during the assessment of Telugu-speaking children with ASD and allow them to choose appropriate goals for management. It would also help in raising caregivers' understanding of feeding problems and their consequences.

## 1.2 Aim of the study

The aim of the current study is to trans-adapt the BAMBI in Telugu and validate this tool on children with Autism spectrum disorder.

# 1.3 Objectives of the study

- 1. To translate and adapt BAMBI to Telugu.
- 2. To determine the content validity of the tool.
- To determine the discriminant validity of the constructed Telugu version of BAMBI by administering the same to children with ASD and typically developing children.
- 4. To determine its concurrent validity.
- 5. To determine the reliability of the tool.

# **1.4 Hypothesis**

There is no significant difference in scores of Brief Autism Mealtime Behaviour Inventory in Telugu (BAMBI-T) between children with ASD and typically developing children.

#### **CHAPTER II**

#### **REVIEW OF LITERATURE**

Individual brain development follows a genetic program that is influenced by environmental factors, including nutrition (Bryan et al., 2004; Toga et al., 2006; Giedd et al., 2010). Food provides energy and nutrients. A child's normal development depends on nutrients that he takes in through the process of eating. Feeding and/or eating is a complex activity that is <u>refined</u> gradually in the developing child. Its normal development is an indicator of neurologic maturation.

#### **2.1 Development of feeding in typically developing children**

Studies done on the development of feeding by Joan et al. (1996) found that infants start to develop feeding skills with suckling on the nipple in the first 4 months after birth and develop the sucking pattern as they progress from liquids to purees at 4-6 months of age. During these early months, a new-born can transition from the early pattern of suckling to real nipple sucking due to changes in the mouth and face, as well as changes in the central nervous system. Between 5 and 7 months, infants begin to learn to obtain semi-solid food from a spoon, progressing to the point where, by 8 months, they can efficiently remove food from the spoon, as documented by Pridham (1990).

After spoon feeding is established, cup drinking is introduced about a month later. Typically, developing infants are ready to start drinking from an open cup with assistance from caregivers between the ages of 6 and 8 months. Initially, they will suckle, protruding their tongue before swallowing, causing the liquid to be lost at the corners of their mouth. Eventually, they will learn to take one or two swallows from a cup held by a caregiver, and by the time they are 9–10 months old, most can drink successfully from a cup held by a caregiver. By the time they are 12 months old, most infants can hold a cup with two hands and take four or five consecutive swallows without choking. As a result, the majority of normally developing infants can drink all liquids from an open cup before their first birthday. Nowadays, with the increasing appeal of "fast food," many children are able to sip from straws by this time.

Most kids start using "soft chewable" for finger feeding between the ages of 6-9 months. These early patterns of chewing involve restricted lateral tongue movements and vertical jaw excursions. Children gradually develop a mature chewing habit with a rotating jaw movement and more lateral tongue excursions as they become more accustomed to certain textures. Over the course of two to four years, chewing abilities for "tougher" items include some meats and raw veggies.

In early childhood, from 3 to 6 years, a special period for the development of food texture preferences is observed. Some of the known factors that could affect the development of preferences in a children include orofacial growth and food rejection tendencies (Chow et al., 2022; Tournier & Forde, 2023). Szczesniak (1972) suggested that all of these children's physiological development is dominant in shaping attitudes to texture. Children's advancements in chewing were primarily attributed to the transition from deciduous ("milk teeth") to permanent adult dentition, which begins at the age of five or six (Gisel, 1988; Le Reverend et al., 2014; Tournier & Forde, 2023). Moreover, children preferring simple and homogenous textures tended to be more food neophobic or picky in eating (Boquin et al., 2014; Laureati et al., 2020; Lukasewycz & Mennella, 2012; Ross et al., 2021; Skouw et al., 2023). These behaviours are observed to be known barriers to children adopting a healthy diet (Dovey et al., 2008).

During the second year of life, toddlers progress to participating in family meals and eating the same foods as their family. While the quantity and size of these foods are small, family meals support the development of children interested in trying new foods while supporting general communication skills in toddlers, and this, in turn, facilitates mealtime interaction and expression of hunger cues.

In the preschool years, around 3-5 years of age, significant increases in initiative, physical and social skills and thought processes occur. Imitation of adults is a common and crucial practice at this stage. As such, it is important that parents demonstrate adaptive behaviours within the realms of social interaction and health practices, including feeding and eating. After ten to sixteen times of exposure to new food, the child starts to accept it. Around mid to late childhood and early adolescence, there may be a plateau in developing taste preferences. Nonetheless, the range and variability of food, as well as certain aversions, are taken to be developmentally typical and are not worrisome. The basic developmental and oral-motor skills associated with feeding progression from birth to 24 months are listed in Table 2 (Arvedon et al., 1996).

# Table 2.1

Developmental and oral-motor skills associated with feeding progression

from birth to 24 months

Age	Progression of	Oral-motor	Developmental skills	
(Months)	liquid and food	skills		
0-4	Liquid	Suckle on nipple	Head control acquired	
4-6	Purees	Suckle off spoon at first	Sitting balance hands midline	
		Suckle to suck		
6-9	Purees	Cup drinking	Hand to-mouth play	
	Soft chewable	Vertical	Reach, pincer grasp	
	grasp	rasp	Limited lateral tongue movements	
9-12	Ground, lumpy,purees	Cup drinking independent	Refines pincer grasp Finger feeding begins	
12-18	All textures	Lateral tongue action emerges	↑ Independence for Feeding scoops food, Brings to mouth	
18-24	More chewable food	Rotatory chewing	↑ food intake	
24 and above	Tougher solids↑	Mature chewing for "tougher"	Total self-feeding ↑ use of fork, cup	
		Solids	Drinking, no spilling	

## 2.2 Common challenges in feeding and eating

Just as personality and individual interest vary from child to child, so do appetite, enthusiasm about food, and size, shape, and growth trajectories. Beginning in infants, babies differ in the frequency and amount of nutrition they consume, as well as their silhouette and physical development. At all stages of development, challenges in feeding and eating can occur. The two predominant concerns parents have about young children's eating involve what appears to be rigidity in eating, which leads to eating small amounts and a limited range of foods or overeating, which parents fear may cause them to become overweight.

Feeding involves a complex process that requires the interaction of the gastrointestinal (GI) tract, cardiovascular system, oropharyngeal mechanism, central and peripheral nervous systems, and support from the musculoskeletal and craniofacial components. This coordinated interaction requires the acquisition and mastery of skills appropriate for a child's physiology and developmental stage. Children are susceptible to feeding issues and related difficulties if any of these systems are disrupted (Bryant et al., 2010). The emergence and persistence of paediatric feeding disorders (PFDs) are frequently caused by the disruption of many systems. Acute or chronic reasons can contribute to the majority of feeding and swallowing difficulties, which are part of a wider range of disabilities. They could progress or remain stagnant.

Feeding difficulties are defined as a condition that negatively impacts a person's development, relationships, mental health, and ability to consume the right nutrients, hydration, or calories at the necessary levels to thrive (Babbitt et al., 1994). The child's health is often at risk when feeding problems occur (Lazaro, 2018). Impaired eating skills can result from altered feeding experiences caused by disease, trauma, or developmental delay. Any time throughout the first few years of life, during

times of change in oropharyngeal architecture and neuromuscular coordination, texture transitions, and transitions in eating/drinking utensils, a neurodevelopmental delay that inhibits feeding may become apparent (Benefer et al., 2013; Shamya et al., 2015). Feeding skills may also be impeded by specific deficits in oral and pharyngeal sensorymotor functioning. Moreover, deficiencies in neurologic functioning (Kumin et al., 1999), abnormal oral structure or function (Vries et al., 2014), altered oral experiences resulting from physical injury, and/or unfavourable or limited feeding experiences can all impair feeding skills (Delaney et al., 2008; Lefton et al., 2006; Morgan et al., 2010; Mussatto et al., 2014). Cloin et al. (2010) outlines the causes of feeding disorders in children, which is depicted in Table 2.2.

## Table 2.2

Causes	Conditions
Anatomic abnormalities of the oropharyx	Cleft lip and/or palate Pierre Robin sequence Velopharyngeal insufficiency Macroglossia Ankyloglossia Retropharyngeal mass or abscess Tonsillar hypertrophy Dental caries
Anatomic/congenital abnormalities of the larynx and trachea	Laryngeal cyst Tracheoesophageal compression from vascular ring/sling Subglottic stenosis Laryngeal cleft Tracheomalacia Laryngomalacia Tracheoesophageal cleft
Anatomic abnormalities of the esophagus	Foreign body Esophageal stricture, web, or ring Tracheoesophageal fistula Congenital esophageal stenosis because of tracheobronchial remnants

Causes of feeding disorders in children

Disorders affecting esophageal peristalsis	Vascular rings and dysphagia lusorum Congenital esophageal atresia Esophageal mass or tumor Chagas disease Pseudo-obstruction Scleroderma Mixed connective tissue disease Systemic lupus erythematosus Polymyositis/dermatomyositis Achalasia Diffuse esophageal spasm
Disorders affecting neuromuscular coordination of swallowing	Rheumatoid arthritis Myasthenia gravis Brain stem glioma Cerebral palsy Postdiphtheritic and polio paralysis Bulbar atresia or palsy Muscular dystrophies and myopathies Rheumatoid arthritis Arnold-Chiari malformation Mobius syndrome (cranial nerve abnormalities) Congenital myotonic dystrophy Oculopharyngeal dystrophy Nitrazepam-induced dysphagia Familial dysautonomia Tardive dyskinesia Polymyositis/dermatomyositis Infant botulism
Disorders that affect appetite, food-seeking behavior, and ingestion	CNS disease (diencephalic syndrome) Deprivation Depression
Metabolic diseases	Organic acidemias Hereditary fructose intolerance Urea cycle disorders
Sensory deficits	Neuromuscular disease Blindness Anosmia Oral hypersensitivity or aversion resulting from a lack of feeding experience during crucial sensitive periods (long-term parenteral or enteral tube feeding)

Conditioned dysphagia	Aspiration Oral inflammation Gastroesophageal reflux Dumping syndrome or gastric bloating after gastric surgery Fatigue (heart disease, lung disease
Mucosal infections and inflammatory disorders causing dysphagia	Epiglottis Herpes simplex esophagitis Adenotonsillitis Chronic graft-versus-host disease Candida pharyngitis or esophagitis Gastroesophageal reflux Cytomegalovirus esophagitis Deep neck space infections Medication-induced esophagitis Laryngopharyngeal reflux from gastroesophageal reflux Behcet disease Caustic ingestion Crohn's disease HIV
Other miscellaneous disorders associated with feeding and swallowing difficulties	Neonatal hyperparathyroidism Williams syndrome Lipid and lipoprotein metabolism disorders Rett syndrome Velocardiofacial syndrome Hypothyroidism Idiopathic neonatal hypercalcemia Trisomy 18 and 21 Neurofibromatosis Prader-Willi syndrome Allergies Coffin-Siris syndrome Xerostomia Optiz-G syndrome Cornelia de Lange syndrome Interstitial deletion (q21.3q31) Globus sensation Epidermolysis bullosa dystrophica

Source: Adapted from Cloin, Smith, and Brown (2010).

The inability or limitation to accept and tolerate liquids and food textures that are appropriate for one's age is caused by impairment in oral sensory functioning. This impairment may be linked to particular qualities of liquid and food textures, such as flavour, texture, viscosity, temperature, bolus size, or appearance (Farrow et al., 2012; Naish et al., 2012). Under reaction, also known as hyposensitivity, is characterised by the following: refusal of liquids and food textures that offer insufficient sensory input; restricted bolus formation; loss of food from the mouth; and lack of awareness of food within the mouth. These children usually seek for larger boluses or ones with intense flavours, temperatures, or sensations. The symptoms of over-response or hypersensitivity typically include gagging at particular textures or bolus sizes and a restricted intake range. These children typically like foods that are room temperature and have finely-grained textures, tiny bolus sizes, and bland flavours.

In a study done by Weir et al. (2012), it was found that inefficient intake, messy eating, poor control over liquids and foods, slow or ineffective bolus formation and propulsion, gagging during bolus formation, and residue after swallowing are all signs of impaired oral motor functioning, which restricts bolus control, manipulation, and/or transit of liquids and solids.

Feeding difficulties are more common in children with neurologic abnormalities, especially when they grow and reach a point where their nutritional needs surpass their feeding abilities (Adams & Elias, 2014). Generally speaking, feeding impairment is higher in children with more severe motor and cognitive disabilities (Arvedson, 2013). Although neurogenic dysphagia is frequent in infancy, it can also manifest later as a result of cerebral palsy, which increases the risk of morbidity and death from persistent aspiration (Christensen, 1989). Paediatric eating issues are also linked to neurodevelopmental disorders, including autism spectrum disorder (Sharpet et al., 2013).

#### 2.3 Feeding issues in children with Autism Spectrum Disorder

According to the DSM-V criteria (2013), social, communicative, and behavioural deficits are characteristics of autism spectrum disorder (ASD). Among the most common issues affecting this population are feeding disorders (Vissoker et al., 2015). ASD is associated with somatic illnesses, which usually include various gastrointestinal tract pathologies, in addition to mental and neurological problems (Cardona et al., 2015; Cole et al., 2017). Food denial, a limited food repertoire, selective eating, and disruptive mealtime behaviours are some of the issues these children face (Bandini et al., 2010). Furthermore, children with ASD frequently show a noticeably diminished interest in food. Food neophobia, irregular eating patterns, frequent food refusal, and particular insistence on food presentation and serving, as well as colour and shape preferences for utensils or packaging, are common behaviours (Stabouli et al., 2021; Pavlovskaya et al., 2021; Margari et al., 2020; Baraskewich et al., 2021). According to DSM-5, food disorders, specifically Pica (Rastam, 2008) and Avoidant/Restrictive Food Intake Disorder (Kenney & Walsh, 2013), were the most commonly reported issues in children with ASD.

These children can get irritable when eating, and they might experience gag when they smell, taste, or even see particular foods (Stabouli et al., 2021; Datta et al., 2023; Chiarotti et al., 2022; Eric et al., 2022; Karigsman et al., 2007; Salari et al., 2022). Remarkably, eating behaviour problems frequently appear in children with ASD before other main indicators of this condition. It is widely established that food problems can seriously impair the everyday functioning of people with ASD and pose a risk to them (Fodstad & Matson, 2008). Some of these feeding issues have been described in detail below.

#### 2.3.1 Food selectivity

The most commonly reported feeding issue in children with ASD has been food selectivity, or the refusal to eat specific types of foods (like meats, vegetables, or crunchy foods) (Cermak et al., 2010). The academic literature is generally in agreement that the most prevalent factor contributing to feeding difficulties in children with ASD is food selectivity. Children with ASD may exhibit food selectivity from an early age and may do so for the rest of their lives. It is typified by a limited range of food choices, consuming specific foods in larger quantities and selectively consuming specific foods, like those high in carbohydrates (Cermak et al., 2010). Food selectivity, sometimes known as "picky eating," is a common eating disorder in children with ASD, putting them at risk for consuming insufficient amounts of essential vitamins and minerals that affect how their cognitive abilities develop (Giovagnoli et al., 2015).

The percentage of children with autism who exhibit dietary selection varies from 17% to 83%. This phrase refers to a wide range of circumstances and actions, such as avoiding particular meals, having an allergy to particular tastes, colours, textures, or temperatures, and adhering to a diet that only includes foods from particular food groups. Food presentation and packaging may also be important (Bandini et al., 2017). Transitioning from paste to solid foods can be challenging. Restricted and stereotyped interests are examples of autistic symptoms that might appear as widespread eating disorders. Difficulty transitioning from paste to solid foods may be an early sign of a symptom of autism, such as restricted and stereotyped interests, which can manifest as pervasive eating disorders. Food selectivity is not limited to lack of variety and food refusal but also includes a restricted diet of fewer than 8–20 dishes, indicating a strong rigidity in food choices and a poor acceptance of new foods (Kanner et al., 1968). Dysfunctional mealtime behaviours such as crying, screaming, escaping, acting aggressively, spitting, throwing food, and chewing without swallowing are frequently present together with this behaviour. Malhi et al. (2021) define food selection as the result of ritualistic and repetitive actions. Moreover, there is a correlation between the severity of autism symptoms and strong food preference in toddlers with ASD (Giovagnoli et al., 2015).

Occasionally, extremely picky eaters with ASD may also fit into the category of food refusal as they are not consuming adequate food to support healthy development and only consume a limited range of foods in large quantities. Food selectivity can have negative health and nutritional effects (Cermak et al., 2010). Parents of ASD children report that they only ate about half of the foods on the list and that they both practised dietary restriction and refusal (Schreck & Williams, 2006). Food selectivity, which manifests as food denial, eating too rapidly, difficulty chewing, stealing food from peers, and vomiting, is the primary problem among the ASD population (Leader et al., 2020).

## 2.3.2 Food Neophobia

It has been found that children with ASD have trouble feeding themselves, are more likely to refuse food, and are less likely to try new foods (Ahearn et al., 2001). Children with ASD frequently exhibit food neophobia, which has a negative impact on their health (Serra et al., 2022). According to Kral et al. (2015), children with autism who also have oral sensitivity issues tend to report more food phobia. Ismail et al. (2020) suggest that challenges in consuming new foods may stem from issues related to taste perception, sensory processing issues, irrational fear of foreign objects, environmental factors, parental and peer modelling, and feeding habits. It was discovered that children with ASD had higher levels of food phobia than their counterparts without ASD.

#### 2.3.3 Disruptive Mealtime Behaviours

Research revealed that parents of children with ASD reported behaviours during mealtime, including issues with feeding routine, overeating, tantrums, gagging, and an altered emotional reactivity. Such mealtime behaviours were of great concern, increasing progressively as their child grew. According to a study done by Provost et al. (2010), 25% of parents whose children were later diagnosed with ASD had expressed concerns about their infants' mealtime habits as early as the first week, 37% during the first year, and 50% during the first one or two years before the diagnosis. According to Gray et al. (2018), the earliest indications of a new eating pattern were visible during the first three months.

A prospective longitudinal cohort study found that children with ASD had trouble establishing a routine for eating as early as six months of age and that these issues continued by the time the infants were 24 months old (Bolton et al., 2012). According to cohort research by Bolton et al. (2012), overeating habits were not always linked to ASD, but infants who were later diagnosed with autism showed a substantial rise in feeding issues and obsessions at 15 and 24 months. In line with this, some ASD clinical records showed food overstuffing being present in children as young as 15 months (Seiverling et al., 2018).

In a cross-sectional study involving 190 pre-schoolers aged 0–2 years who were later diagnosed with ASD, mealtime behaviours were solely characterised by crying (Barnevik et al., 2013). Consistent with these findings, a case study of a 28month-old child diagnosed with autism in the USA reported additional mealtime behaviours such as screaming and tantrums when others ate, as well as other issues like gagging and vomiting after meals (Barnhill et al., 2016).

According to a cohort study (Brisson et al., 2012), children with ASD (n = 13) showed distinctive anticipation when the spoon neared their lips at mealtime (p = 0.008) compared to infants with typical development (n = 14). In a study done by Bryson et al. (2007), it was documented that a female child with autism, at the age of 12 months, could only be soothed by her mother's slow singing, tickles, or bottle-feeding during mealtime.

#### 2.3.4 Food Refusal

High rates of food refusal were seen in children with ASD, as evidenced by behaviours like disengagement during mealtimes, eating very little, or having poor appetite (Keen et al., 2007). Parents stated that their infants, who were later diagnosed with ASD, began to refuse breast milk at 6 months of age and avoided eating solid foods, according to findings from a cohort study (Bolton et al., 2012). "ASD has been associated with a decrease in accepting to eat certain foods, stated Bolton et al. (2012). Refusal to try new foods was more common in the ASD group (10.3%) than in the language-delayed group (0%), according to a chart review research in which 54% of language-delayed children and 45% of ASD children were younger than 24 months (p = 0.002). Cornish (Cornish et al., 1998) identified a challenging transition from mashed food to solid food among children with ASD, as difficulties in the introduction of new foods and, as a result, refusal to new foods.

Several case studies also indicated the same finding. The ASD case of Keen et al. (2007) included a child who refused to eat solid foods until the age of two and drank excessive amounts of milk to the point of vomiting, indicating problems with solid

foods. A 12-month-old infant who was subsequently diagnosed with ASD persistently rejected any food that wasn't smooth, according to Bryson et al. (2007). All parents of ASD cases (n = 17), according to Cornish et al. (1998), stated that their infants were eating everything up until the age of 12 months, when a nutritional regression to eating nothing was noticed, along with skill loss and developmental delays. Similar circumstances were described in a case report in which a 15-month-old baby began to reject all foods at once and was subsequently given an ASD diagnosis (American Psychiatric Association, 2013). Some authors have suggested that the presence of feeding difficulties in infancy may be an early sign of ASD (Amaral et al., 2008; Laud et al., 2009,).

#### 2.4 Factors that could contribute to feeding issues

#### 2.4.1 Sensory selectivity

Unusual sensory processing in ASD is important, though rarely acknowledged. Touch, smell, and taste are among the senses where this phenomenon is most noticeable. Children with ASD are more likely to experience this phenomenon than children with other developmental disorders or typically developing (Chistol et al., 2018). Sensory processing is a problem for 78–90% of children with ASD (Leekam et al., 2007). According to Laud et al. (2009), high prevalence rates of feeding issues in ASD are commonly attributed to sensory impairment/defensiveness in the literature.

Consequently, the resulting sensory sensitivities frequently manifest as underor over-responsivity, characterised by enhanced or negative reactions to sensory inputs, or as a combination of the two. These persistent sensory abnormalities are independent of age or the severity of ASD, and they can be identified as early as early childhood and continue for the course of the person's lifetime (Zobel et al., 2015). Sensitivity, particularly within the oral sensory domain, significantly affects dietary behaviours. There is a link between food selectivity in ASD and sensory processing malfunctions with a specific focus on oral sensory sensitivity (Chistol et al., 2018; Cremak et al., 2010; Stolar et al., 2021; Suarez et al., 2012; Zobel et al., 2015)Food selectivity in ASD is associated with sensory processing issues, particularly with regard to oral sensory sensitivity. Children who have unique oral sensory sensitivities reject a wider range of foods and consume fewer vegetables than children who do not have these sensitivities (Rodrigues et al., 2023). On the other hand, a deficiency in taste sensitivity is associated with heightened symptoms of eating disorders. Additionally, increased symptoms of eating disorders and eating behaviours unique to ASD are correlated with increased sensitivity in the visual domain (Stolar et al., 2021).

Food acceptability and choice are influenced by food texture and taste (Proserpio et al., 2017). According to Pellegrino et al. (2020), food texture is important, plays a crucial role in the eating process, and can determine whether a food is accepted or rejected. Before serving new meals to young children, they should first explore through touch. Youngsters who demonstrate sensory defense might be less inclined to eat with their hands, especially food items that are slimy and mushy (Ernsperger & Hanson, 2004). Sensory aversions are seen in children with ASD (Schreck et al., 2004). The majority of kids also had problems with tactile sensitivity, and nearly 60% of them did not like having their hands or faces dirty (Emmons et al., 2005).

Studies suggest that children with ASD respond atypically to olfactory stimuli (Muratori et al., 2013). Difficulties distinguishing between different smells and recognising basic smells can lead to problems with food selectivity and a reduced variety of foods consumed (Bennetto et al., 2007). According to Dudova et al. (2011), olfactory dysfunctions may also indicate a biomarker for autism.

Children with ASD exhibit a more severe and widespread impairment in their sensory processing compared to children without the disorder. This has an impact on their eating habits. Children in both ASD and non-ASD subgroups showed a hyporesponsive profile. Compared to children without ASD, children with ASD had more severe impairments in Under-responsive/Seek sensation and Auditory Filtering. Only those diagnosed with ASD exhibited significantly reduced olfactory sensitivity. Furthermore, a subgroup of children with ASD showed a more severe impairment in their ability to sense touch (Panerai, 2020).

In a study done on children with autism, they frequently scored higher on the oral sensory processing section, demonstrating enhanced atypical oral sensory processing. Unlike other oral sensory issues, most of the children were picky eaters, particularly regarding food textures. In addition, their food repertoire was limited to certain food textures, and they could only eat particular flavours. Furthermore, past research found that children with autism had more severe oral sensory problems (Hazen et al., 2014).

## 2.4.2 Gastrointestinal Problems

Gastrointestinal (GI) problems are found to be more prevalent in children with ASD compared to their typically developing peers. These problems include issues such as constipation, diarrhea, and gastroesophageal reflux, which can cause significant discomfort and pain during eating. This discomfort can lead to food aversions and further exacerbate feeding difficulties. Children may avoid eating altogether or restrict their diet to foods that they perceive as safe and non-painful (Mannion & Leader, 2014).

Gastrointestinal issues have been reported to affect children with ASD in a range of 9 to 91% of cases (Coury et al. 2012). A high prevalence of GI symptoms has been documented in literature, indicating that these issues may affect a significant proportion of children with ASD.

Additionally, the presence of GI symptoms can negatively impact an individual's quality of life. Williams et al. (2010) found that children with ASD who experience GI symptoms have a lower quality of life compared to those without such symptoms, indicating that GI complaints are associated with an overall decrease in health-related quality of life.

GI problems might be influenced by food. According to Kuddo and Nelson (2003), children with autism may desire stereotyped meals deficient in fiber, water, or other nutrients as a result of the emphasis on sameness in the condition. Finally, there may be adverse effects if youngsters are taking medicine. According to Kuddo and Nelson (2003), the majority of medications given to autistic children can have an impact on gastrointestinal function.

# 2.5 Management of feeding issues in children with ASD

Managing feeding issues in children with ASD requires a comprehensive, multi-disciplinary approach. Behavioural interventions, particularly cognitivebehavioural therapy (CBT), are effective in addressing feeding difficulties. Programs like the Building up Food Flexibility and Exposure Treatment (BUFFET) gradually expose children to new foods, helping them become more flexible eaters and reduce mealtime anxiety (Burton et al., 2021; Kuschner et al., 2017). Food chaining, a technique that introduces new foods similar to those already accepted by the child, also shows promise in expanding dietary variety without causing distress (Volkert & Vaz, 2010). Additionally, a team of dieticians, occupational therapists, speech-language pathologists, and behavioural psychologists can collaborate to develop individualised treatment plans. These professionals work together to address sensory sensitivities, behavioural challenges, and nutritional needs, ultimately aiming to improve the child's overall feeding experience and nutritional intake (Telesford, Santoro, & Martin, 2021; Bourne, Mandy, & Bryant-Waugh, 2022).

Feeding problems in children with ASD can have far-reaching consequences that affect not only the child but also the entire family. These challenges can manifest as nutritional deficiencies, growth delays, and behavioural issues, which can lead to increased stress and anxiety for parents and caregivers. The ripple effect of these problems extends to the family's quality of life, often causing disruptions in daily routines, social activities, and emotional well-being. To mitigate these impacts, it is crucial to manage feeding problems effectively. This begins with a thorough assessment to identify the specific issues and their severity. By understanding the nature and extent of feeding difficulties, tailored intervention strategies can be developed to improve the child's eating habits and overall health, thereby enhancing the quality of life for the entire family.

## 2.6 Tools used for assessment

Assessing feeding issues in children with ASD is crucial for understanding and addressing the unique challenges that they face. Proper assessment tools provide structured and reliable methods to identify specific feeding problems, enabling the development of effective intervention strategies. Several tools are available, each designed to capture different aspects of feeding difficulties. These range from questionnaires based on caregiver observations to performance-based assessments involving direct observation of the child's eating behaviours. Behavioural observations involve direct observation of the child's eating habits during meals to identify problematic behaviours and patterns. Feeding assessments conducted by occupational therapists evaluate the child's oral motor skills, sensory responses, and mealtime behaviours through structured activities. These assessments provide a comprehensive understanding of the child's feeding difficulties and guide the development of personalised intervention strategies.

These tools are essential for several reasons. They help pinpoint the exact nature of feeding problems, whether behavioural, sensory, or related to oral motor skills. Accurate assessment allows for the development of tailored intervention strategies that address each child's unique needs. Repeated assessments can track changes over time, helping to adjust interventions as needed. Furthermore, clear insights into the child's challenges help families understand the issues better and collaborate more effectively with healthcare providers. Given the complex nature of feeding issues in children with ASD, using a combination of these tools provides a comprehensive understanding, facilitating better management and improved outcomes. Some of the tools available to assess feeding difficulties in children with developmental disorders are listed below.

## 2.6.1 Children's Eating Behaviour Inventory (CEBI)

In order to assess the attitudes and behaviours of children, parents, and family members during mealtime for children of all ages with a variety of developmental and medical issues, Archer et al. (1991) developed this test. The 28 items in the tool are associated with the child's motor development, dietary preferences, and behavioural compliance. Twelve questions address relationships within the family as well as parent behaviour and the family structure, including what parents think and feel about feeding their children. This survey evaluates the frequency of 40 feeding and mealtime practices. Parents use a 5-point Likert scale to rate each behaviour, marking "Yes" or "No" to indicate whether they think the behaviour is a problem or not. The instrument possesses valid psychometric properties and has been validated. It is helpful because it inquires about the attitudes of parents and kids during mealtimes. However, the majority of the questions don not specifically address the eating habits that are commonly observed in children with ASD.

# 2.6.2 The Screening Tool for Feeding Problems (STEP)

STEP was developed by Matson and Kuhn (2001) in order to evaluate eating difficulties that people with intellectual disabilities (ID) have in terms of aspiration risk, food selectivity, deficiencies in feeding skills, food refusal and related behavioural concerns, and nutrition-related behaviour issues. This tool was originally normed on individuals diagnosed with ID in the age range of 10-87 years. Later, the Turkish version of STEP was Trans-adapted and validated on a population with ASD by Meral et al. (2013) and concluded that it was an effective assessment tool to measure feeding issues in school-age ASD children, whose average age was 9 years. STEP is a parent-reported questionnaire which comprises 23 items, with questions relating to vomiting being associated with a high risk of aspiration (i.e., regurgitation of consumed food). Food selectivity is evaluated in selectivity questions with respect to feeder, meal environment, temperature, food kind, and texture. The ability to swallow, chew, and feed oneself on one's own, as well as the requirement for adaptive

feeding devices, are among the questions surrounding feeding capacities. Questions relating to food refusal include spitting food out of one's mouth, acting angrily during meals, and injuring oneself while eating. For each question, there are three possible answers: (0 = never occurs, 1 = occurs between 1 and 10 times, and 2 = occurs more than 10 times) and (0 = causes no harm or problems, 1 = causes minimal harm or problems, and 2 = causes serious injury or problems) regarding feeding difficulties experienced within the previous month. In the study by Matson et al. (2000), cut-off scores were established to categorize the severity of feeding difficulties. Scores between 0 and 7 indicated no or minimal feeding difficulties. Individuals scoring between 8 and 11 were classified as having moderate feeding difficulties, while those with scores of 12 or above were considered to have severe feeding difficulties, necessitating immediate medical attention (Matson et al., 2000).

## 2.6.3 Behavioural Paediatrics Feeding Assessment Scale (BPFAS)

Crist and Napier established the BPFAS, a robust and reliable measure that effectively differentiates children with clinically significant eating issues in normative and clinical samples (Crist & Napier-Phillips, 2001). It is composed of a set of 35 standardized and validated items used to assess feeding behaviour in typically developing children age ranging from 9 months to 7 years and across a range of non-ASD paediatric populations (e.g., normative group, children with CHARGE syndrome, children with cystic fibrosis, children with diabetes, and overweight/obesity (Crist & Napier-Phillips, 2001; Crist et al.,1994; Davis, Canter, Stough, Gillette, & Patton, 2014; Dobbelsteyn, Peacocke, Blake, Crist, & Rashid, 2008; Patton, Dolan, & Powers, 2006).

BPFAS was a widely used parent-report measure to assess mealtime and feeding behaviour. Among the 35 items, 25 focus on the feeding behaviour of the child

(e.g., takes longer than 20 minutes to finish a meal; enjoys eating; has problems chewing foods), and the remaining 10 evaluate the parent's perspectives and coping strategies regarding the child's eating habits, including mealtimes and eating challenges feeding problems (e.g., I get frustrated and/or anxious when feeding my child; I feel confident my child gets enough to eat). The assessment utilizes a five-point Likert scale, where responses range from 1(never) to 5 (always). Positively phrased items are reverse-scored. Greater overall scores indicate higher levels of problematic mealtime and feeding behaviour. Stephanie et al. (2015) conducted a study using BPFAS on preschool children with ASD and found BPFAS to be clinically useful in assessing behavioural issues during feeding. BPFAS has been validated in the Telugu language spoken in the Indian states of Telangana and Andhra Pradesh by Prasanna et al. (2023). Additionally, it has been demonstrated that BPFAS-T has sufficient validity and reliability for measuring mealtime behaviour in kids with ASD (Prasanna et al., 2023).

# 2.6.4 The Parent Mealtime Action Scale Revised (PMAS-R)

Hendy et al. (2009) created the Parent Mealtime Action Scale (PMAS) to assess feeding problems in children in the age range from two to twelve years, with and without ASD and developmental disabilities. The PMAS-R is a validated tool for assessing parent feeding practices in clinical settings, with applications in understanding feeding behaviours and their impact on child health and development, particularly in populations with special needs such as ASD (Helen et al., 2016). Parents completed questionnaires to report child demographics and diet habits using a fivepoint rating (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always), instead of the original three-point rating to report their usage of the 31 PMAS feeding practices. The scale measures various aspects of parent-child feeding interactions. Nine subscales, including ones for snack restrictions, positive persuasion, daily access to fruits and vegetables, use of rewards, insisting on eating, snack modelling, special meals, fat reduction, and various other topics, make up the PMAS.

## 2.6.5 The Swedish Eating Assessment (SWEAA)

This questionnaire was devised by Karlsson et al. (2013). This tool consists of an 81-item multidimensional self-reported structured questionnaire to evaluate eating disorders in ASD in the ages of 15-25 years. This questionnaire consists of 60 questions, and it is divided into 8 subdomains. The subdomains are perception, motor control, food purchases, eating behaviour, meal setting, and social situations during meals, additional behaviours related to eating disorders, and hunger. These items are rated using a 5-point Likert scale where one indicated never, and five indicated always. The internal consistency of this test is found to be high.

# 2.6.6 The Brief Autism Mealtime Behaviour Inventory (BAMBI)

One of the tools developed and used specifically for children with ASD is The Brief Autism Mealtime Behaviour Inventory (BAMBI). It is also a widely used feeding questionnaire for children with ASD in clinical and research studies. Lukens and Linscheid (2008) designed BAMBI as the first standardized informant report measure to capture mealtime and feeding behaviours explicitly in children with ASD. According to Seiverling et al. (2010), this tool was found to be a promising psychometric assessment of feeding functions in children with ASD. This questionnaire includes a wide range of problematic behaviours that are frequently seen in this population and can be used in clinical practice to diagnose feeding problems in children with ASD quickly and accurately. In the original questionnaire, twenty items were divided into three domains: oral defensiveness, tactile defensiveness, sensory oversensitivity in the mouth, and nutritional selectivity (Tomchek & Dunn, 2007; Williams et al., 2000; Lane et al., 2010; Baranek et al., 2007). However, the authors drew attention to its shortcomings and modified it after six years. The revision comprised 18 items and rates the frequency of specific behaviours using a Likert scale (1 = Never/Rarely to 5 =Almost Every Meal). The scale yields a total score, as well as scores on three domains. Items 10, 11, 13, 14, 15, 16, 17, and 18 in the restricted variety factor measures the child's openness to experimenting with new foods and foods that differ in preparation, texture, and type. Five factors make up the food denial factor (items 1, 2, 4, 7, and 8), which describes the problematic behaviours that are shown when a kid rejects food that has been offered to them. The characteristic component of ASD (items 3, 5, 6, 9, and 12) includes elements that indicate the behavioural traits of ASD, such as self-aggressive and stereotyped actions during meals. The questionnaire is completed by the parents/caregivers (Castro et al., 2019). Reverse-scoring was observed for item numbers 3, 9, 10, and 15 to obtain a frequency score, which is calculated as the sum of the Likert responses.

Lamboglia and a group of researchers of Italian rehabilitation and healthcare professionals translated original English version of BAMBI into Italian language adhering to International standards. They recruited children in the age range of 6-10 years. A total of 131 children were chosen from a community and clinical sample, of which included 90 children who are typically developing and 47 children diagnosed with ASD. A systematic review was conducted to determine the equivalency between the original and Italian versions of BAMBI. During the translation process, some of the items such as items 8 and 18, were changed to better adapt to the Italian culture. Cross-cultural validity was obtained through participant observation, which was closely correlated to the intended meaning of the original items. For test-retest reliability, they chose 30 participants from the original sample according to their participation availability, and they used repeated measurements of the same participants after 2 days. Excellent test-retest reliability was found for every BAMBI item (range: 0.83–1.00). With a Cronbach's Alpha of 0.86 and 0.71 for TD and ASD children, respectively, internal consistency showed significant data. They also computed whether differences in gender exist and their results showed no significant differences between females and males. Additionally, they also looked into variations in body mass index and gender, but they could not find any significant differences between the groups. To summarize, the Italian translation of the BAMBI demonstrated strong test-retest reliability and internal consistency, making it suitable for both clinical and research settings (Lamboglia, 2023).

BAMBI questionnaire was translated into Turkish (Meral et al., 2014) and was validated on 308 children with autism. 240 of the children were male, and 61 were female. It had 14 questions after final translation, modification, and validation. The results of the confirmatory factor analysis made under the validity studies showed that the Turkish version of the BAMBI questionnaire has an acceptable goodness fit. Under reliability measures, it was determined that both the split-half reliability values and the internal consistency coefficient were high. The item-total correlations of the scale were also determined to be satisfactory. According to Meral's (2014) findings, the scale can be considered reliable and valid for evaluating the behaviour of children with ASD during mealtimes in Turkey.

Nguyen Minh Huong translated BAMBI into Vietnamese and validated the same. The tool's 18 questions were found to have excellent internal consistency, with Cronbach's alpha > 0.7 for all of them. Following the exploratory factor analysis, four questions were eliminated (EFA). A total of 194 parents of children diagnosed with ASD participated in the study. The Vietnamese BAMBI is a valid and trustworthy measuring tool for evaluating mealtime and feeding difficulties in children with ASD, according to the confirmatory factor analysis, which revealed that the tool is thought to be fairly close to the fit model (CFI < 0.9) (Huong, 2021).

BAMBI was also translated into Portuguese as the Breve Registro de Comportamento Alimentar- Transtorno do Espectro do Autismo (BRCA-TEA) questionnaire by Castro et al. (2019). In this study, a large population comprised 410 participants (205 parents of children with ASD and 204 parents of typically developing children). The discriminant validity analysis revealed that the ASD group had significantly higher mean scores across all three domains of the instrument, as well as overall, compared to the typically developing group, indicating that the instrument is capable of discriminating between the two groups. A commonly reported feeding issue among patients with ASD in this study is the limited variety of food intake. This questionnaire yielded a cut-off value of  $\geq$  47 with a sensitivity of 0.82 and a specificity of 0.27.

BAMBI was also translated to one of the Indian languages i.e., Malayalam by Tomson (2023). In this study, the original BAMBI was translated and adapted to Malayalam and validated it on children with ASD. This study included 30 parents/caregivers of children with ASD and 30 parents/caregivers of typically developing children of age 3-11 years. BAMBI-M is found to be a very sensitive tool for identifying feeding-related issues in children with ASD with an excellent test-retest reliability (0.95). With a Cronbach's Alpha of 0.71, internal consistency in children with ASD was good across various items. They obtained a cut-off score of 31 points. This study also found that there was no correlation between feeding issues and age.

## 2.7 Studies done in children with ASD using BAMBI

Several studies have used BAMBI to document the feeding issues in children with ASD. Some of them have been described below. Zobel and colleagues (2015) examined sensory differences and mealtime behaviours in children with ASD compared to typically developing (TD) peers aged 5 to 12. They utilised parent-report and child-report questionnaires to assess sensory differences and eating behaviours. The results indicated that children with ASD scored significantly differently from TD peers in terms of sensory differences and eating behaviours. Importantly, there was a correlation between sensory differences and eating difficulties in children with ASD. These findings highlight the impact of sensory factors on mealtime behaviours and emphasise the need for strategies, including those offered by occupational therapy practitioners, to enhance mealtimes for children with ASD and their families.

Aponte and Romanczyk (2016) conducted a study involving 36 children with ASD, aged between 3.5 and 12.5 years (mean age = 6.9 years) to assess mealtime behaviours using the BAMBI scale. The study found that the children exhibited a wide range of mealtime behaviours, with a mean total BAMBI score of  $45 \pm 12$  (range 18-90). Specific dimensions of mealtime behaviour were also measured, including food selectivity (mean =  $10.2 \pm 4$ , range 5-25), disruptive mealtime behaviours (mean =  $25.3 \pm 7.1$ , range 8-40), and food refusal (mean =  $9.4 \pm 3.3$ , range 5-25). The findings highlighted the variability and intensity of these behaviours in children with ASD, demonstrating the utility of the BAMBI scale in quantifying problematic mealtime behaviours and aiding in the development of targeted interventions and support strategies for this population.

The mealtime behaviours of 31 Chinese-American children with ASD were examined in a study using BAMBI. They found that parents identified the following as the three most problematic mealtime behaviours: prefer "crunchy" food (54.2%), are not willing to try new foods (48%), and leave the table before the meal is finished (46%). According to this study, 92.3% of the Chinese-American children with ASD were disruptive during mealtimes, and 96% of them were rarely or never aggressive. Chinese-American children with ASD scored marginally lower on problematic mealtime behaviours than their white peers (Gray, 2017).

#### 2.8 Need for tools in the Indian context

A look into the existing literature revealed that feeding problems are indeed prevalent in children with ASD and that there are limited questionnaires/tools to assess these problems in the Indian context. A study conducted on the Asian population revealed that there is a higher prevalence of ASD in Asia compared to Western nations. However, despite this higher prevalence, a significant portion of research on feeding behaviour and challenges in individuals with ASD originates from Western countries. This poses a potential limitation, as findings from Western population may not fully capture or reflect the food-related issues experienced by Asian individuals with ASD, due to cultural differences in eating habits. In many Western studies, the tools and assessments developed to understand feeding challenges in ASD individuals have been primarily validated and standardized within Western cultural contexts. There is a scarcity of culturally adapted tools in India compared to Western countries, which lays down the need to develop such tools in the Indian context as well.

Given these considerations, the present study was designed to address the gap in understanding feeding behaviours and challenges among individuals with ASD in the Asian context, particularly in India. By focusing on cultural nuances and specific dietary practices prevalent in Asian communities, this study aims to provide insights that are more relevant and applicable to the local population. This approach acknowledges the importance of cultural sensitivity in research and aims to contribute to a more comprehensive understanding of feeding issues in ASD across diverse cultural backgrounds.

## **CHAPTER III**

# METHOD

The current study aimed to Trans-adapt and validate the Brief Autism Mealtime Inventory (BAMBI) in Telugu. The primary objectives of the study were to determine the validity (content, discriminant and concurrent validity) and reliability (test-retest reliability) of the constructed Telugu version of BMABI on children with ASD. The study was carried out in two stages: Stage 1 was to translate and culturally adapt BAMBI, and Stage 2 was to validate the tool and assess its reliability.

### **3.1 Stage 1: Translation and Adaptation of the BAMBI questionnaire.**

The widely accepted American Association of Orthopaedic Surgeons (AAOS) rules, which include the forward-backward translation approach, were used to translate all of the questions. Permission from the authors who developed the BAMBI questionnaire was acquired through mail. The permission obtained through email has been attached as Appendix I. The translation and adaptation process was carried out using the following five steps.

- 1. Forward translation
- 2. Synthesizing common translation
- 3. Backward translation
- 4. Expert committee review
- 5. Pre- final testing

# 3.1.1. Forward translation

The English version of the BAMBI questionnaire was taken for translation from English "source" to the Telugu language, which was the "target" language. Two bilingual individuals were involved. One of them was a qualified translator, and the other was a speech-language pathologist (SLP) with three years of experience and expertise in feeding-related issues. Both of their first languages are Telugu. Both the translators had produced individual translations (F1 and F2). The translators attempted to translate terms or phrases logically rather than literally. They were instructed prior, to consider the original term's definition into account without translating it word-forword. They focused on the comprehensibility of the items by an ordinary layman respondent rather than professional audiences. Cultural variations were incorporated during the translation process. Instructions that were given to the translators were as follows:

- The questions should be translated into simple, clear, concise, and to the point.
- Lengthy sentences must be avoided.

• The translated questionnaire must be easy to comprehend for the general population.

• It is crucial to use language that is appropriate and non-offensive when crafting questions.

## 3.1.2 Summary of translation

A third independent team member (a qualified translator) produced a single consolidated translation after addressing disparities between the independent translations. Since each translator had their own linguistic preferences and word choices, the simpler, clearer, and more colloquial of the two versions was chosen.

# 3.1.3 Backward translation

Subsequently, two bilingual adults from a non-medical background individually translated the common synthesised translation back into English (B1 and B2). These two translations (B1 and B2) were done independently, and they had no knowledge of the original version of the questionnaire.

## 3.1.4 Expert committee review

This group included three skilled SLPs who were bilingual Telugu-English speakers. The committee examined all of the translations and suggestions were given pertaining to grammar and synonyms of a few words to achieve equivalency. Also, the items 3, 9, 10 and 15, which were positively phrased were reverse scoring in the original BAMBI has been rephrase in this study. Apart from this changes, few additions in the examples were added for item 16, i.e., "My child prefers to have food served in a particular way". The examples given were about having preference for "colour" or "shape of the food". For item 18, the example was changed from that of original English version to a more culturally appropriate example. The examples in the item 18, "My child prefers food prepared in a particular way" (e.g., eats mostly fried foods, cold cereals, raw vegetables), were replaced with "curd rice" and "fried foods".

# 3.1.5 Field testing of pre-final version

This prefinal version questionnaire was administered to 15 primary caregivers of children with ASD. This was the last step before creating the translated questionnaire's final form. Using the preliminary questionnaire form, participants were interviewed individually with respect to their understanding of the items and words. Along with their answers to the questions, each participant's perspective on how he or she perceives the question was gathered. Participants were enquired whether any questions or items were difficult to understand or irrelevant to them. The suggestions given by the parents were about the addition of questions relating to olfactory sensitiveness and texture preferences for certain food items. The opinions and responses were reviewed, and made sure that the translation was accurate and required modifications were made before the questionnaire was ready. All the revisions mentioned above led to the final BAMBI version of the Telugu questionnaire.

After the responses from the participants and expert panel committee, two items were added; those were item 19, "My child likes or dislikes smells of certain food items", item 20, "My child avoids certain food items because of its texture (e.g., wet food items/ slimy consistency foods)". These items were added under the domain of Characteristics of ASD.

# **3.2 Content validation**

The BAMBI-T questionnaire was validated for its contents by three SLPs with more than three years of professional experience in treating feeding difficulties in children with ASD. They were instructed to evaluate all sections of the assessment tool, considering the appropriateness of the questions, using a 4-point rating scale where 1 indicated lower relevance and 4 indicated higher relevance. Clarity, representativeness, ambiguity, and cultural appropriateness were also taken into account when rating. Content validation scores obtained indicated a high relevance, clarity, representativeness, no ambiguity and cultural appropriateness by three SLPs and no changes were recommended. The final questionnaire has been attached as Appendix II.

## 3.2.1 Stage 2: Validation of translated questionnaires

This stage included validation of the translated BAMBI-T on children with feeding problems secondary to ASD.

**Participants:** Native Telugu-speaking caregivers of children with ASD and typically developing children in the age group of 3-11 years were enrolled in the study and

divided into two groups. Group 1 consisted of 60 primary caregivers of children with ASD (M = 44.82, SD = 11.51), of which 40 children were males, and 20 were females. Group 2 included 30 primary caregivers of typically developing children (M = 21.90, SD = 2.41), of which 16 were males and 14 were females. The participants were included through convenience sampling. Caregivers of children undergoing speech-language and/or occupational therapy services, whose children were diagnosed with ASD using Childhood Autism Rating Scale–2 (CARS-2; Schopler et al. 1980, 1988) and or Indian Scale For Assessment of Autism (ISAA; Deshpande, 2008) by a team of professionals, including a speech-language pathologist, clinical psychologist, and occupational therapist, were recruited from clinics/centres located in the state of Telangana and from the Department of Clinical Services and Preschool training center, AIISH, Mysuru. Those children identified to have feeding deficits by a speech-language pathologist through an informal screening were included.

The children in the group 2 were selected from the regular schools of Hyderabad and Telangana and through camps conducted by Church and other organizations. Each child was examined informally before enrolling in the study to rule out the presence of speech and language disorders and neurological, oromotor, psychological, physical, and sensorimotor disorders. Only those participants without any of these problems were included in the study.

## **Inclusion criteria**

The following inclusion criteria were used.

• The caregivers should be able to read and write Telugu, with a minimum educational qualification of tenth grade.

• Caregivers aged 18 and above.

• The caregiver who had fed the child for at least two months of time period.

# **Exclusion criteria**

- Parents/ caregivers of children with any other associated problems such as sensory (hearing and vision), neurological, and psychological problems.
- Primary caregivers with other health issues or psychiatric illnesses.

# **3.3 Ethical Consideration**

The study adhered to the ethical standards for biobehavioral research involving human subjects as established by the AIISH ethical committee. The selection and participation of the participants fully complied with all ethical guidelines. The study was explained to parents/primary caregivers of children with ASD and typically developing children who met the criteria for inclusion. Parents who agreed to participate were contacted, and consent was obtained. They ensured the safety and confidentiality of the participant's details.

# **3.4 Procedure**

Routine demographic details about the child's age, weight, and height, the number of siblings, and any developmental disabilities the child was taken. Parents were provided with the BAMBI-T questionnaire, and they were asked to complete it. Parents were seated in a quiet room without distractions while answering the questionnaire. Every parent received instructions on how to read the questions and choose the most appropriate responses.

## 3.5 Test-retest reliability

In order to assess the test-retest reliability, BAMBI-T was re-administered on 10% of participants after one week of their initial response to ensure that the underlying construct being measured is stable over this short period.

## **3.6 Concurrent validity**

To establish concurrent validity, the Behavioural Paediatric Feeding Assessment Scale in Telugu (BPFAS-T, Prasanna et al., 2023) was administered to children with ASD. BPFAS was originally developed by Crist and Napier-Phillips (2001) for assessing behavioural and skill-based feeding issues in both normative and clinical populations. It is a valid and reliable measure that successfully distinguishes children with clinically significant feeding issues (Crist & Napier-Phillips, 2001). The assessment utilises a five-point Likert scale, where responses range from 1(never) to 5 (always). Positively phrased items are reverse-scored. An increase in scores on this scale typically indicates greater severity of problem behaviour. BPFAS appeared to be a valid tool for assessing feeding problems in pre-schoolers with ASD. It identifies common feeding problems, such as food refusal and oral-motor difficulties. BPFAS was developed in English and many other languages, including Telugu, a language of the Indian states of Andhra Pradesh and Telangana. BPFAS-T questionnaire was found to be a reliable and valid tool for measuring behaviour problems during mealtime in ASD children (Prasanna et al., 2023).

## **3. 7** Statistical analysis

The total scores of each item of both the questionnaires (BAMBI-T and BPFAS-T) were computed for each participant. Using Statistical Package for Social

Sciences (SPSS v26.0 for Windows; SPSS Inc., Chicago, IL), the obtained values were tabulated and subjected to suitable descriptive statistics to obtain mean, median and standard deviation for both the groups. The tests of normality such as Kolmogorov-Smirnov and Shapiro-Wilk tests was done. The discriminant validity of the translated tool was assessed using Mann-Whitney test. Cronbach's alpha was used to determine the internal consistency of the tool. Spearman's rho correlation analysis was done to assess the test- retest reliability and concurrent validity. The level of significant association between the caregiver's response on each BAMBI-T test item and the groups was measured using the Chi-square test. The results have been discussed in the next chapter.

## **CHAPTER IV**

# RESULTS

The primary aim of this study was to translate, adapt, and validate the English version of the Brief Autism Mealtime Behavioural Inventory (BAMBI) questionnaire into Telugu, an Indian language. This study was conducted in two phases. The first phase involved the translation and cultural adaptation of the BAMBI questionnaire into Telugu. The translation process followed AAOS guidelines, including forwardbackward translation. Forward translation was carried out by two bilingual professionals, which synthesised two versions. Backward translation was carried out by two bilingual speakers and a summary of the translated questionnaire was synthesised. Then, the expert committee reviewed the questions required, additions were made and pre-final testing was done with primary caregivers of children with Autism Spectrum Disorder (ASD). At this stage, two questions were added to the domain of characteristics of ASD, based on the inputs from the participants. Content validation was conducted for the prefinal version of BAMBI-T by three experienced speech-language pathologists (SLPs), who rated the appropriateness of the questions on a 4-point rating scale and a final BAMBI-T questionnaire was obtained, which comprised of 20 items.

The final BAMBI-T comprised of three domains viz. Food denial factor, Restricted variety and characteristics of ASD. Each item on BAMBI is evaluated by the caregivers based on the frequency of specific behaviours using a Likert scale (1 =Never, 2 = Rarely, 3 = Occasionally, 4 = Often, 5 = Almost Every Meal). This scale provides a total score as well as scores across three domains. Items 10, 11, 13, 14, 15, 16, 17, and 18 within the restricted variety factor assesses the child's willingness to try new foods and foods with different preparations, textures, and types. The food denial factor, consisted of items 1, 2, 4, 7, and 8, and describes problematic behaviors exhibited when a child rejects offered food. The ASD characteristic component, comprised of items 3, 5, 6, 9, 12, 19 and 20, which includes elements that reflect behavioral traits of ASD, such as self-aggressive and stereotyped actions during meals. A high score on the scale suggests that the specific behavior described by each item had a significant and persistent issue in the child's mealtime routines, potentially indicating notable challenges in feeding and mealtime behaviors.

In the second phase, the adapted Telugu version (BAMBI-T) was administered on 60 children with ASD (group 1) and 30 typically developing children (group 2) aged between 3 and 11 years for the purpose of validation. The concurrent validity was assessed by administering the Behavioural Paediatric Feeding Assessment Scale in Telugu (BPFAS-T, Prasanna et al., 2023) to children with ASD. BPFAS assesses behavioural and skill-based feeding issues. The test-retest reliability was assessed by re-administering BAMBI-T on 10% of participants after one week of their initial response.

The overall score for each participant in both groups for both the tests was calculated by adding the individual score on each item based on the rating scale. The obtained data was tabulated and subjected to appropriate statistical analysis. The following statistical procedures were carried out using SPSS software (version 26.0). The obtained data was analysed for the normality using tests such as Kolmogorov-Smirnov and Shapiro-Wilk's tests for both ASD and typically developing (TD) groups. The ASD group data was closer to a normal distribution, whereas the data of the TD group did not follow a normal distribution. Descriptive statistics was carried out to obtain mean, median and standard deviation for both the groups.

Discriminant validity was assessed using the Mann Whitney U-test. Cronbach's alpha was used to determine the internal consistency of the tool. Chi-square test to measure the level of significant association between the caregiver's response on each test item of BAMBI-T and the groups. Spearman's rho correlation analysis was done to assess the concurrent validity and test-retest reliability. The results are presented under different sections below.

#### 4.1 Test-retest reliability

To assess the test-retest reliability, BAMBI-T was re-administered on 10% of participants after one week of their initial response to ensure that the underlying construct being measured is stable over this short period. The spearman's rank correlation coefficient was used to assess the consistency or stability of BAMBI-T over time. The spearman-rho (p) value obtained was found to be 0.9, indicating excellent reliability.

## 4.2 Internal consistency of BAMBI-T

The internal consistency of items was assessed among children with ASD using Cronbach's coefficient alpha. Internal consistency is a measure of the reliability of a test, indicating how well the items on the test measure the same construct or concept. The Cronbach's alpha value obtained was 0.84, indicating good reliability. This means that the test items are consistently measuring the same construct related to feeding difficulties.

# 4.3 Comparison of BAMBI-T scores between children with ASD and typically developing children

Descriptive statistics was computed for the data from both the groups.

A clear-cut distinction in the BAMBI-T scores was found between the two groups. The mean value of the participants in group 1 (children with ASD) was higher compared to group 2 (TD children). Among group 1, the highest and lowest score obtained was 81 and 22, respectively, whereas the highest and lowest score obtained in the group 2 was 45 and 20, respectively. There was no overlap between the ranges of scores of both groups indicating a clear distinction in the feeding issues. The BAMBI-T scores in group 1 was found to be wider in range and higher compared to group 2. The mean values of group 1 was also greater than the mean value of group 2. The minimum and maximum score along with the mean, standard deviation and the median scores of group 1 and 2 are given in the table 4.1.

# Table 4.1

Minimum and maximum score, mean, standard deviation and the median scores of both groups

	Group 1	Group 2
BAMBI-T scores	(Children with ASD)	(TD children)
	(n=60)	(n=30)
Maximum score	81	45
Minimum score	22	20
Mean	44.82	21.90
SD	11.51	2.41
Median	45.50	21.50

## Note: SD- Standard deviation

The total mean scores and the total score of each of the three domains of the tool, that are Food denial factor (FDF), Restricted variety (RV) and Characteristics of ASD (CASD) of both the groups, were subjected to the Mann Whitney U-test. The

results revealed a high significant difference between the ASD group (M=44.8, SD=11.51) and the TD group (M= 27.30, SD=6.04), with a p-value of < 0.00 for the total and domain scores. Group 1 (children with ASD) had significantly higher scores when compared to group 2 (TD children), suggesting that children with ASD exhibited markedly higher feeding difficulties compared to typically developing children. Table 4.2 depicts the /z/ and p values. Thus, the hypothesis that there was no significant difference in scores of Brief Autism Mealtime Behaviour Inventory in Telugu (BAMBI-T) between children with ASD and typically developing children was rejected.

# Table 4.2

Results of Mann-Whitney test for total mean score and mean of each domain of BAMBI-T.

BAMBI scores	ASD (n=60)	TD (n = 30)	/Z/	р
Total mean scores	44.82 (±11.51)	27.30(± 6.04)	6.39	0.00*
Domain mean scores				
Food denial factor (FDF)	9.97(±3.49)	5.97(±1.58)	5.84	0.00*
Restricted variety of food (RV)	21.77(±7.02)	14.67 (±4.61)	4.68	0.00*
Characteristics of ASD (CASD)	13.08(±4.03)	6.67(±0.95)	7.06	0.00*

## 4.4 Distribution of responses on each item of BAMBI-T across both groups

The responses obtained from the caregivers of both groups on the BAMBI-T have been depicted in table 4.3. The results indicated that the items under the Restricted food variety (RV) domain had the highest frequency of occurrence, when compared to other domains, such as food denial factor (FDF) and characteristics of ASD (CASD). The chi-square ( $\chi$ 2) test was done to measure whether significant differences, if any, existed in the different aspects of feeding between both the groups for each item. The chi square values ranged from 5.05 to 35.78. The results of the test revealed that the items FDF 2, 4 & 7; RV, 10, 11, 13, 15, 17, & 18 and CASD 3, 6, 9, 12, & 20 were significant at 0.05 level. However, there was no significant difference in the items FDF 1 & 8, RV 14 & 16, and CASD 5 & 19 between both the groups. The frequency of occurrence of responses for all the items on BAMBI-T in both the groups, chi-square ( $\chi$ 2) values and degrees of freedom are depicted in Table 4.3.

# Table 4.3

Percentage of occurrence of responses on each item of BAMBI-T in both groups and

		Group	1 (ASD)				Group	2 (TD)			
Q. no.	Never	Rarel y	occasi onally	Ofte n	Alwa ys	Never	Rarel y	Occas ionall y	Often	Alwa ys	χ2
FDF 1	50.0 %	30.0 %	13.3 %	5.0%	1.7%	76.7 %	16.7 %	6.7%	0.0%	0.0%	6.60
FDF 2	26.7 %	28.3 %	38.3 %	3.3%	3.3%	73.3 %	23.3 %	3.3%	0.0%	0.0%	21.69
FDF 4	71.7 %	11.7 %	11.7 %	3.3%	1.7%	100%	0.0%	0.0%	0.0%	0.0%	10.47 <sup>*</sup>
FDF 7	43.3 %	21.7 %	13.3 %	8.3%	11.7 %	90.0 %	10.0 %	0.0%	0.0%	0.0%	10.47 <sup>*</sup>
FDF 8	55.0 %	18.3 %	10.0 %	5.0%	11.7 %	83.3 %	13.3 %	0.0%	0.0%	3.3%	8.85
RV 10	18.3 %	16.7 %	10.0 %	30%	25.0 %	76.7 %	20.0 %	3.3%	0.0%	0.0%	35.78 <sup>3</sup>
RV 11	41.7 %	13.3 %	16.7 %	16.7 %	11.7 %	46.7 %	36.7 %	13.3 %	0.0%	3.3%	11.97 <sup>;</sup>
RV 13	38.3 %	15.0 %	16.7 %	10%	20.0 %	80.0 %	13.3 %	0.0%	3.3%	3.3%	16.67 <sup>;</sup>
RV 14	36.7 %	10.0 %	13.3 %	15%	25.0 %	23.3 %	3.3%	26.7 %	23.3 %	23.3 %	5.05
RV 15	30.0 %	16.7 %	23.3 %	15%	15.0 %	80.0 %	20.0 %	0.0%	0.0%	0.0%	26.83
RV 16	66.7 %	10.0 %	15.0 %	3.3%	5.0%	86.7 %	13.3 %	0.0%	0.0%	0.0%	8.29
RV 17	65.0 %	15.0 %	6.7%	0.0%	13.3 %	50.0 %	13.3 %	20.0 %	10.0 %	6.7%	10.78 <sup>3</sup>
RV 18	40.0 %	18.3 %	16.7 %	11.7 %	13.3 %	80.0 %	13.3 %	6.7%	0.0%	0.0%	15.30 <sup>3</sup>
CASD 3	41.7 %	15.0 %	23.3 %	15%	5.0%	80.0 %	20.0 %	0.0%	0.0%	0.0%	18.69 <sup>;</sup>

chi-square values.

CASD 5	75.0 %	11.7 %	10.0 %	1.7%	1.7%	100%	0.0%	0.0%	0.0%	0.0%	9.00
CASD 6	61.0 %	13.6 %	11.9 %	5.1%	8.5%	100%	0.0%	0.0%	0.0%	0.0%	15.77*
CASD 9	48.3 %	13.3 %	11.7 %	8.3%	18.3 %	100%	0.0%	0.0%	0.0%	0.0%	23.64*
CASD 12	53.3 %	16.7 %	6.7%	10%	13.3 %	90.0 %	10.0 %	0.0%	0.0%	0.0%	13.71*
CASD 19	51.7 %	13.3 %	18.3 %	8.3%	8.3%	60.0 %	12.2 %	16.7 %	5.6%	5.6%	7.56
CASD 20	21.7 %	11.7 %	26.7 %	18.3 %	21.7 %	70.0 %	23.3 %	6.7%	0.0%	0.0%	30.11*

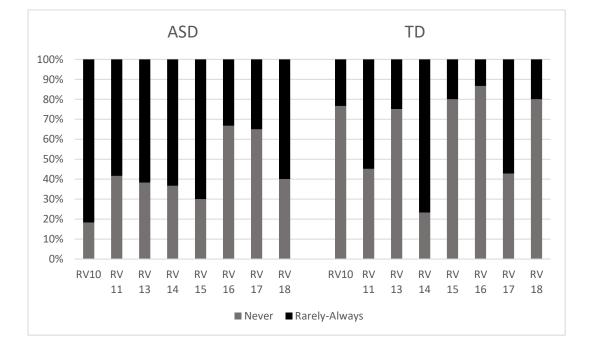
# *Note:* \* Indicates significant at 0.05 level

Upon reviewing the items in the Restricted Variety (RV) domain, item 10, 13 and 15 which identifies unusual mealtime behaviours like having restricted food repertoire, mealtime rituals such as preferring the same foods at each meal and not willing to try new food were reported in children with ASD over a range of 61.7 % to 81.7% when considering the sum of scores of BAMBI-T from 'rarely' to 'Always'. However, the response rates of the caregivers of TD children for the same items varied between 19.9% to 23.30% for these items.

A greater preference was seen for 'crunchy' foods (RV14) and sweet food items (RV17) in TD children than in children with ASD, however, the difference between groups was less pronounced (76%, 50% in TD vs. 63%, 35% in ASD). The response rates for the item RV11 (Dislike for certain foods) were near similar in both groups, with a slightly increased rate among the children with ASD (58.4% in ASD, 53.3% in TD).

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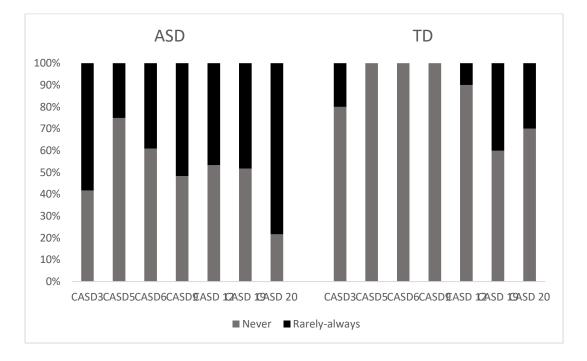
A large proportion of caregivers of TD children reported 'never' for most items, indicating fewer issues in this domain. This trend was particularly noticeable in RV10, RV13, RV15, RV 16 and RV18. The distribution of responses on each item under the domain of Restricted variety of food (RV) among children with ASD and TD has been depicted in Figure 4.1.



**Figure 4.1:** *Distribution of responses on each item under the domain of Restricted variety of food (RV) for categories 'Never' and 'Rarely' to 'Always' among children with ASD and TD children.* 

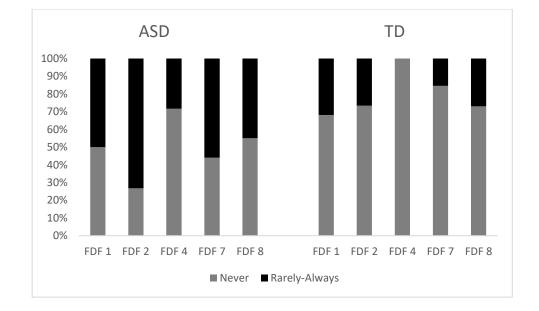
Upon reviewing the most frequently occurring responses under the domain of characteristic of ASD (CASD), items 20 and 9 were most frequently rated by the caregivers of children with ASD with the responses being >50%, when the sum of responses from 'rarely' to 'always' were considered. Item 20 focussed on the avoidance of certain foods due to its texture and item 9 explored the flexibility of mealtime routines. However, in the TD children, only 30% of parents reported 'never' occurred or even if occurred it was observed 'rarely' and 'occasionally'. Further, for

items 9, 6 and 5, all the responses from the TD group were found to be under category of "never", which revealed that these items relating to aggressive mealtime behaviours and self-injurious behaviours were distinctive features, that distinguished children with ASD from the TD children. The distribution of responses on each item under the domain of characteristics of ASD (CASD) among children with ASD and TD has been depicted in figure 4.2.



**Figure 4.2** Distribution of responses on each item under the domain of characteristics of ASD (CASD) for categories 'Never' and 'Rarely' to 'Always' among Children with ASD and TD children.

Children with ASD exhibited persistent mealtime challenges, including food refusal and distress during the mealtime, due to sensory aversion thus developing strong food preferences. This was seen on reviewing the most frequently occurring responses under the domain of food denial factor (FDF). The most frequently occurring problem behaviours with respect to FDF that were exhibited by children with ASD were FDF 7 ("My child is disruptive during meal time"), and FDF 8 ("My child closes mouth tightly when food is presented"), with a notable proportion of children with ASD exhibiting these behaviours for 'Almost every meal' (Figure 4.3). It also indicated that the frequency of problem behaviour were much less among the TD children. More than 90% of responses by their caregivers fell under the category of 'Never' and 'Rarely".



**Figure 4.3** Distribution of responses on each item under the domain of Food denial factor (FDF) for categories 'Never' and 'Rarely' to 'Always' among children with ASD and TD children.

# 4.5 Concurrent validity

To establish concurrent validity, the Behavioural Paediatric Feeding Assessment Scale in Telugu (BPFAS-T, Prasanna et al., 2023) was administered to children with ASD. BPFAS assesses behavioural and skill-based feeding issues. It utilises a five-point Likert scale, where responses range from 1(never) to 5 (always). Positively phrased items were reverse-scored. A higher score on this scale typically indicates greater severity of problem behaviour. Using Spearman's rho correlation, it was found that BAMBI-T had a weak positive correlation (r = 0.44) (Al-Hameed, 2022) with BPAS-T.

# 4.6 Sensitivity and specificity of BAMBI-T

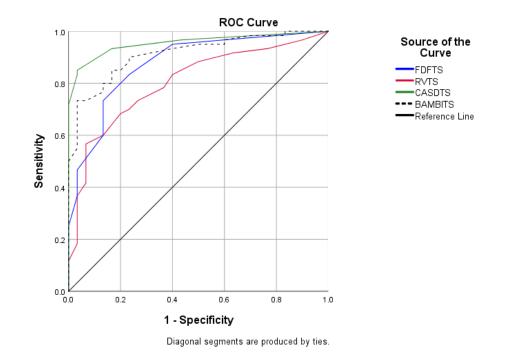
A Receiver Operating Characteristic (ROC) curve was generated by plotting the true positive rate (sensitivity) against the false positive rate (specificity) for BAMBI-T scores, comparing group 1 and group 2 across various threshold settings. The sensitivity and specificity values and the cut off score for each domain and the total score are presented in table 4.4. The coordinates of the ROC curve and the corresponding sensitivity and specificity values for specific domains has been depicted in figure 4.4.

# Table 4.4

	Domain	ı specific	sensitivity,	specificity an	nd cut-off score	for BAMBI-T
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Do	omain	Sensitivity	Specificity	Cut-off score
FI	OFTS	83%	77%	6.5
R	VTS	73%	74%	16.5
CA	ASDTS	93%	84%	7.5
BA	AMBITS	85%	84%	32.5

Note: FDFTS- Food denial factor total score; RVTS- Restricted variety total score; CASDTS-Characteristics of Autism spectrum disorders, BAMBITS- Brief Autism Mealtime Behavioural inventory total score.



**Figure 4.4:** *ROC curve and the corresponding sensitivity and specificity values for specific domains*.

The Receiver Operating Characteristic (ROC) analysis revealed cut-off scores with corresponding sensitivity and specificity for distinguishing between children with ASD and TD children across different domains. Under the Food Denial Factor Total Score (FDFTS) domain, a cut-off score of 6.5 yielded a sensitivity of 83% and specificity of 77%, demonstrating moderate accuracy in distinguishing between the groups. In the Restricted Variety of Food Total Score (RVTS) domain, a cut-off score of 16.5 achieved a sensitivity of 73% and specificity of 74%, also demonstrating moderate accuracy in distinguishing between the groups. The Characteristics of Autism Spectrum Disorder Total score (CASDTS) domain showed the highest sensitivity of 93% and a specificity of 84% at a cut-off score of 7.5, making it particularly effective in identifying ASD. BAMBI-T total scores (BAMBITS) yielded a cut-off score of 32.5 and a sensitivity and specificity of 85% and 84% respectively,

indicating a very high sensitivity and specificity for the BAMBI-T. This indicated that BAMBI-T had higher probability of detecting the presence of feeding issues in children with ASD. These findings highlight the efficacy of the identified cut-off scores in accurately classifying ASD and TD children across various behavioural assessment domains.

To sum, the results of the current study revealed a significant difference for the domain specific and total mean scores across groups, with significantly higher scores for children with ASD, indicating greater feeding issues in this group. There was a significant difference on all items except 1, 5, 8, 14, 16, and 19. The test-retest reliability, internal consistency, specificity and sensitivity was high indicating that BAMBI-T was a valid and reliable tool to effectively identify feeding issues in children with ASD.

### **CHAPTER V**

#### DISCUSSION

The Brief Autism Mealtime Behavioral Inventory (BAMBI) is the first tool designed specifically for parents to evaluate feeding challenges in children with ASD (Lukens & Linscheid, 2008). It was developed to standardize information on the nutrition and feeding habits unique to children with ASD. This questionnaire addresses numerous problematic behaviors common in this population that other assessments overlook, making it an efficient and precise clinical tool for identifying feeding issues in children with ASD. The trans-adaptation and validation of BAMBI into Telugu, enables the integration of a structured examination for this population into clinical practice.

In the current study, the original English BAMBI was translated and adapted to Telugu (BAMBI-T), adhering to the guidelines provided by American Association of Orthopaedic Surgeons (Thammaiah et al., 2016). The pre-testing phase enabled cross-cultural validity and proved to be strictly in agreement to the meaning of the original words used in the BAMBI. The tool was finally validated on 60 parents of children with ASD. The reliability, internal consistency and concurrent validity was also assessed. The concurrent validity was assessed by administering BPFAS-T on the same set of children with ASD.

The data obtained was subjected to appropriate statistical analysis using SPSS software (version 26.0). Descriptive statistics was carried out to obtain mean, median and standard deviation for both the groups. Discriminant validity was assessed using Mann Whitney U-Test and Cronbach's alpha was used to determine the internal

consistency of the tool. Chi-square test to measure the level of significant association between the caregiver's response on each test item of BAMBI-T and the groups. Spearman's rho correlation analysis was done to assess the concurrent validity and test-retest reliability. The results have been discussed in different sections below.

#### **5.1 Translation and adaptation of BAMBI**

The first objective of the study was to achieve a trans-adapted version of BAMBI in Telugu. The forward translation resulted in two distinct Telugu versions of the questionnaire. Subsequently, two other individuals performed a backward translation to evaluate the accuracy of the questionnaire. An appropriate consolidated version was then developed after an expert review validated the content. Throughout these simultaneous revisions, corrections and substitutions of words were made, creating a culturally adaptable tool. This tool was deemed adequate in terms of simplicity, familiarity, applicability, complexity, clarity, and cultural appropriateness. Opinions and perspectives of experts were gathered during the four stages of translation and field study. Based on feedback from participants and the expert panel review, two additional questions were incorporated.

The final version of the BAMBI-T comprised of 20 items, organized into three domains. The restricted variety of food (RV) domain comprised of 8 items, which assessed the openness of the child to experiment with new foods and foods that differ in preparation, texture, and type. The food denial factor (FDF) domain included 5 items, which assessed, how often a child refuses food or displays negative behaviors when food is presented. It included behaviors like crying, turning away, spitting out food, and refusing foods that require chewing. The domain on characteristics of ASD encompassed 7 items, which assessed elements that indicate the behavioural traits of ASD, such as self-aggressive and stereotyped actions during meals.

The newly added items was included under the domain of characteristics of ASD (CASD). One of the items that was added to BAMBI-T was about smelling food items. Bennetto et al. (2007) found that children with ASD often exhibited abnormal responses to olfactory stimuli, which may result in developing strong aversions to foods with particular smells, resulting in avoidance of certain foods, thus limiting their diet variety and potentially leading to nutritional deficiencies. Kern et al. (2006) reported that the sensory abnormalities in ASD, including olfactory processing creates a significant barrier to trying new food, which contributes to the feeding problems in them.

The second item that was newly added to BAMBI-T was regarding dislike of touching certain foods because of its slimy or wet texture. Sensory aversions are a common challenge in children with autism. Children with autism often exhibit strong preferences and aversions related to food textures, significantly influencing their eating behaviors. Schreck et al. (2004) found that these children often exhibit strong sensory aversions, which can make mealtime particularly challenging. According to Proserpio et al. (2017), food acceptability and choice are largely influenced by the texture and taste of the food. Pellegrino et al. (2020) emphasized that food texture plays a crucial role in the eating process, often determining whether a food is accepted or rejected. This is particularly relevant for children with autism, who may exhibit heightened sensory sensitivities.

#### **5.2 Clinical validation of BAMBI-T**

Validation of BAMBI-T was the second objective of this study. To achieve this, the final version of BAMBI-T was administered on 60 parents/caregivers of children with ASD and 30 parents/caregivers of typically developing children. Following the statistical analysis of the data, a substantial difference in scores between the typical and ASD groups was found. The mean total score obtained for children with ASD and TD was 44.82 and 27.30 respectively. This is in agreement with the findings by Luken and Linscheild (2007), who also found the mean total score to be 49 and 32.5, respectively for children with ASD and TD. All the domain scores of BAMBI-T, including food refusal domain, restricted variety and characteristics of Autism and the total scores showed a statistically significant difference between the two groups. The study involving trans-adaptation of BAMBI to Portuguese (BRCA-TEA inventory, Castro et al., 2019) also reported similar findings.

Several other studies exploring feeding issues also report that children with ASD have greater feeding issues than typically developing children (Vissoker et al., 2015). According to Martin et al. (2008), children with ASD were more likely to exhibit ritualistic eating patterns, selective eating and food refusal when compared to typically developing peers. Children with autism exhibit more feeding issues, troublesome feeding patterns, and limitations in accepting particular food groups and novel foods compared to typically developing children (Sahan et al., 2021). The prevalence of problematic eating and feeding behaviors is a key distinguishing factor between children with ASD and their typically developing peers (Martins et al., 2008). Unlike children with other developmental disorders and those who are typically developing, children with ASD encounter feeding difficulties more often and in a broader variety (Schreck et al., 2004).

A review of the occurrence of responses of caregivers of the ASD group revealed that the items under the Restricted food variety (RV) domain had the highest frequency of occurrence in comparison to other domains. In the RV domain, high proportion of caregivers reported that children with ASD had greater difficulties in trying new foods (food neophobia). They also had unusual mealtime behaviours like having restricted food repertoire and mealtime rituals such as preferring the same foods at each meal.

The food neophobia could be due to aversion towards certain foods, leading to limited food repertoire. According to Bloissett et al. (2013), a person's irrational fear of unfamiliar objects, sensory processes, taste perception, surroundings, peer and parental modeling, and feeding habits can all contribute to their difficulty consuming new food. Stereotypical food choices and aversion to novel tastes are common in children with ASD (Stafford et al., 2017). Additionally, research has shown that children with ASD exhibit more disruptive behavior during meals than peers in usual peer groups (Gentry & Luiselli, 2008), particularly when introduced novel foods.

Research has consistently shown that children with ASD often exhibit strict and repetitive eating habits. For instance, Schreck et al. (2004) noted that ritualistic eating behaviors are more common in children with ASD compared to their neurotypical peers. These behaviors can manifest as an insistence on specific mealtime routines or the consumption of foods in a particular order or manner. Moreover, Baker (2000) highlights that inflexibility and rigidity in children with ASD extend across various adaptive behavior domains, including play, conversation, and eating. This rigidity is particularly evident during meals, where children with ASD often insist on nonfunctional routines that can disrupt family meals and make it challenging to introduce new foods.

Children with ASD in the present study also showed a higher tendency to prefer the same foods at each meal and rigidity in how food is served and prepared. This finding is in consonance with the study by Leiva García et al. (2019), who found that children with ASD accepted limited foods, often leading to nutritional deficiencies due to their rigid feeding practices and preference for a consistent diet. Similarly, Ledford and Gast (2006) noted that children with ASD frequently insist on specific foods and engage in mealtime rituals, such as eating the same food prepared in the same way, consuming food in a particular order, and avoiding new foods. Schreck et al. (2004) further highlighted that children with ASD consume a much narrower variety of foods compared to their typically developing peers, with a tendency to prefer processed and carbohydrate-heavy foods while rejecting fruits, vegetables, and proteins. Caregivers in this study also reported that they practised dietary restrictions of avoiding dairy products and goods high in glucose or carbs, which induced a narrow food repertoire.

Preference for 'crunchy' foods" was observed in 63% of children with ASD and 53% of typically developing children, indicating that this behaviour was prevalent in both groups. There are evidences that support this finding that food texture preferences, such as a preference for crunchy foods, are common in children with ASD, but are also prevalent among typically developing children. Evans et al. (2021) found that texture preferences in children with ASD are not markedly different from those in their typically developing peers, highlighting that food texture sensitivities are a shared characteristic across these groups. Similarly, Suarez et al. (2020) reported that while children with ASD exhibit more pronounced food selectivity, specific texture preferences like crunchy foods were observed in the typically developing children as well.

However, other studies have found that children with ASD also exhibit strong preferences for certain textures, particularly favouring crunchy textures (Huxham et al., 2021; Ranjan et al., 2015). Catino et al. (2019) also reported that frequent mealtime problem behaviors in children with ASD include a preference for crunchy foods, food neophobia, and difficulties remaining seated at the table during meals. These differences could be because of the food related and dietary differences between India and other countries.

In a review of the next domain that assessed the characteristic features of ASD, the Majority of parents reported that their children refused to touch food of wet or slimy texture indicating high tactile sensitivities. In addition, rigid mealtime behaviours was predominantly observed in children with ASD. The majority of children in both groups preferred to have the food only with a spoon, as reported by parents in this study. Item 12 which assessed about how often the child refused food that requires a lot of chewing, revealed that majority of parents of children with ASD raised a heighted concern that their child did not prefer to chew rice, instead they would swallow the rice directly.

Recent studies have highlighted various tactile sensory issues observed in children with ASD. These children often exhibit heightened sensitivity to touch, significantly impacting their daily lives and behaviors. For example, children with ASD may have an over reactivity to light touch, which can be perceived as uncomfortable or even painful, affecting their ability to tolerate certain textures and physical contact, leading to picky eating habits, especially with foods that have mushy or slippery textures (Orefice et al., 2019).

Tactile sensory abnormalities in children with ASD can be linked to differences in how their nervous system processes touch. The somatosensory system, which includes neurons controlling the sense of touch, can influence behaviors associated with autism, and understanding these mechanisms can lead to potential therapeutic interventions targeting tactile overreactivity. Atypical sensory processing, including tactile sensitivity, can affect adaptive functioning and contribute to maladaptive behaviors in children with ASD. Their sensitivity to certain textures can lead to difficulties in various daily activities, including eating and grooming (Dellapiazza et al., 2020). Emmons et al. (2005) reported that the majority of children with autism also had issues with tactile sensitivity, with nearly 60% expressing a dislike for having their hands or faces dirty. This tactile defensiveness can further contribute to their reluctance to eat foods with certain textures, such as those that are slimy or wet.

Items 3, 5, 6 and 9 assessed the rigid mealtime routines, aggressive behaviours and self-injury behaviours. This was reported to be present to a greater extent in children with ASD when the responses from 'rarely' to 'always' are combined. Catino et al. (2019) reported frequent mealtime problem behaviors in children with ASD including difficulties remaining seated at the table during meals. Aggressive behaviors in children with ASD, such as tantrums and self-injury, are often linked to their rigid routines and sensory sensitivities, including mealtime routines. These children may exhibit strong preferences for specific seating arrangements and become distressed if their routine is disrupted. This rigidity and need for consistency can lead to aggressive outbursts when changes occur (O'Nions et al., 2018; Marquenie et al., 2011).

Other studies have reported the presence of problematic feeding behaviors in children with ASD. Lane et al. (2014) found that many children with ASD exhibit a lack of flexibility regarding mealtime routines. These children may display aggressive behaviors or self-injury if their routines are disrupted, and they often have difficulty remaining seated at the table during meals. Such behaviors can significantly impact their nutritional intake and social interactions during meals, highlighting the need for targeted interventions to address these challenges. The Food Denial Factor (FDF) in the BAMBI-T assessed challenging behaviors in children with ASD during mealtimes such as resistance to eating, aversive reactions to food, and disruptive behaviors such as crying or screaming, turning away from food, spitting out food, and being disruptive during meals, as well as closing the mouth tightly when food is presented.

The findings of the present study revealed that turning away their food/ body away from the food was predominantly observed in children with ASD. Crying during meal time and refusing to open mouth when food is presented was observed in 50% in children with ASD and in around 20% TD children. Cermak et al. (2010) also noted aversive reactions in children with ASD. Spitting of food which also seen in a large proportion of children with ASD. Vissoker et al., (2015) also reported that the frequency of chewing and spitting is rising in children diagnosed with ASD. Sahan et al. (2021) also reported disruptive eating behaviors such as spitting out food, banging spoons, rejecting food, running from the eating area, crying, and yelling in children with ASD.

#### 5.3 Sensitivity and specificity of BAMBI-T questionnaire

In the current study, the cut-off score was obtained using the Receiver Operating Curve (ROC) curve, which had a sensitivity and specificity of 85% and 84% respectively. The obtained cut-off point was 32.5. According to this study, children with ASD who score 32.5 or higher may have feeding-related problems.

Sensitivity and specificity are two key metrics used to evaluate the performance of a diagnostic test. Sensitivity is the ability of the test to correctly identify those with the condition (true positives) and specificity indicates the test's ability to correctly identify those without the condition (true negatives). A sensitivity

of 85% indicated that BAMBI-T is good at identifying children with ASD who have feeding issues and a specificity of 84% indicated that BAMBI-T is good at ruling out those without the feeding issues. Overall, these values suggest that the test was fairly accurate and reliable.

According to Tomson (2023), the BAMBI-M questionnaire in Malayalam had a cut-off score of 31, which is similar to the cut off score found in the present study. In the study done by Castro et al. (2019), where the BRCA-TEA questionnaire, also known as the BAMBI questionnaire in Portuguese was developed, the cut-off value obtained was 47, sensitivity was 0.81 and specificity was 0.27. The present study obtained a slightly higher sensitivity and specificity values compared to the study by Castro et al. (2019).

#### 5.4 Test-retest reliability

The test-retest reliability of BAMBI-T, as indicated by Spearman's rho coefficient was 0.94 with a p-value < 0.05, which demonstrated excellent test-retest reliability. These findings are similar to the values reported in various studies. Lukens et al. (2007), the authors of original BAMBI found high test-retest reliability value of 0.87 in their study. Similar findings were observed in the studies done on other translations of BAMBI. The study done by Gray et al. (2017) reported a test-retest reliability of 0.90 and Aponte et al. (2016) also found test-retest reliability value of 0.88.

## **5.5 Internal Consistency**

The internal consistency, as measured with Cronbach's coefficient alpha, in the present study was 0.84. This finding is in consonance with the studies in which the BAMBI was trans-adapted to various languages. The internal consistency of the Turkish version of BAMBI was 0.79 (Kaya et al., 2018), the Brazilian version of BAMBI was 0.70 (Almeida et al., 2017) and the Vietnamese version was 0.78 (Nguyen et al., 2019). The study in which the original version of BAMBI was developed, reported the internal consistency as 0.88 (Lukens & Linscheid, 2008).

#### **5.6 Concurrent validity**

To assess the concurrent validity of BAMBI-T tool, Behavioural Paediatric Feeding Assessment Scale in Telugu (BPFAS-T) was utilised, which evaluates behavioral and skill-based feeding issues using a five-point Likert scale. Higher scores on the BPFAS-T indicate greater severity of feeding problems. Spearman's rho correlation analysis revealed that BAMBI-T had a weak positive correlation (r = 0.44) (Al-Hameed, 2022) with BPAS-T. Similar concurrent validity was demonstrated in a study by Lukens et al. (2007) using the English version of the BPFAS, where a correlation of 0.77 was reported. The observed difference in correlations could result from a combination of factors, including participants from different demographic backgrounds, such as the age range and sample size, severity of autism symptoms, and nature of feeding difficulties.

#### **CHAPTER VI**

#### SUMMARY AND CONCLUSIONS

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by limited, repetitive activities and an inability to communicate and connect socially (DSM V). There has been substantial literature on feeding difficulties observed in children with ASD. However, not many research studies have been done to understand the feeding problems in the Indian setting. This could be due to the nonavailability of questionnaires to document the feeding deficits. It is imperative that feeding behaviors in children with ASD be evaluated using standardized questionnaires.

The Brief Autism Mealtime Behavior Inventory (BAMBI) is a specialized validated questionnaire to assess mealtime behaviours in children with ASD between the ages of 3 and 11. Developed to capture the unique challenges and behaviors exhibited by children with ASD during mealtime, BAMBI is completed by parents or caregivers who observe their child's mealtime patterns in natural settings. As feeding issues are increasingly recognized as significant concerns for children with ASD, BAMBI plays a crucial role in identifying specific behaviors and challenges.

The current study is to adapt and validate the BAMBI into Telugu. The original BAMBI was translated and cross-culturally adapted in compliance with the process of adaptation recommendations from Thimmaiah et al. (2016), in line with the standards of the American Association of Orthopaedic Surgeons (AAOS). The questionnaire was translated and adapted in five stages: forward translation, common translation synthesis, backward translation, expert committee review, and field testing. In the field study, 15 caregivers of children with ASD participated and evaluated the

familiarity, simplicity, applicability, complexity, clarity, and cultural appropriateness of all the items. The final BAMBI-T had 20 items covering three domains: characteristic features of ASD (CASD), food denial factor (FDF), and Restricted variety factor (RV). The questionnaire was validated by administering it on 30 caregivers of typically developing children and 30 caregivers of children with ASD within the age range of 3-11 years.

The overall score for each participant in both groups was calculated by summing the individual item scores based on the rating scale. The data was tabulated and subjected to statistical analysis using SPSS software (version 26.0). Descriptive statistics, including mean, median, and standard deviation, were obtained for both groups. Normality was assessed using the Shapiro-Wilk test. Discriminant validity was evaluated using the Mann-Whitney U-Test, while Cronbach's alpha determined the internal consistency of the tool. The chi-square test measured the significant association between caregiver responses on each BAMBI-T item and the groups. Spearman's rho correlation analysis assessed concurrent validity and test-retest reliability.

The scores on BAMBI-T for the typically developing children was found to be between 20 and 45, whereas the range for the ASD group was between 22 and 81. Mann-Whitney U-test revealed significantly higher scores in children with ASD compared to typically developing children across the total scores and the three domains of the tool. The ASD group exhibited markedly higher feeding difficulties (M=44.8, SD=11.51) than the typically developing group (M= 27.30, SD=6.04), with a p-value of <0.05, indicating significant differences. These findings highlight that the BAMBI-T was able to effectively distinguish mealtime behaviours predominantly observed in children with ASD, further solidifying its utility in assessing feeding difficulties. The child's willingness to try new food was the most rated problem behaviour with 81.7% of frequency of occurrence observed in children with ASD.

Internal consistency through Cronbach's alpha was found to be 0.84, indicating good consistency. The tool's test-retest reliability was found to be high, with an obtained value of 0.94 using Spearman's rho correlation coefficient. The Receiver Operating Characteristic (ROC) curve could be used to distinguish between these values clearly. The sensitivity and specificity of this test were found to 85% and 84%, which was high, and the cut-off value obtained was 32.5.

The BAMBI-T demonstrated excellent test-retest reliability, internal consistency, sensitivity, and specificity, making it valuable for clinical and research applications. The BAMBI-T was found to be a highly sensitive tool for identifying feeding-related issues in children with ASD. The clear distinctions in scores between children with ASD and typically developing children underscore the importance of early identification and intervention for feeding challenges in ASD.

#### 6.1 Limitations of the current study

The developed tool is limited to assessing children with ASD who are between the ages of 3 and 11, which restricts its applicability to other age groups. The severity of ASD was not accounted for in this study, potentially overlooking variations in feeding issues related to different levels of ASD severity. The study involved 60 children with ASD and 30 typically developing children, but this relatively small and homogeneous sample size may limit the generalizability of the findings. Furthermore, the significant gender imbalance, with more males than females, precluded any meaningful gender-specific analysis. Other potential factors, such as socio-economic status, family type, and age of identification of feeding problems, were not considered, which could have provided a more comprehensive understanding of the issues.

## **6.2 Clinical implications**

• The present study developed a self-assessment tool for Telugu-speaking caregivers of children with ASD who have feeding difficulties.

• The results of this study emphasise how crucial it is to deal with sensory and selectivity issues that arise when feeding autistic children.

• This tool can serve as a quick screening instrument to assess feeding issues in children with feeding difficulties, and those having a score above the given cut-off scores can be promptly referred for further detailed evaluation.

• The tool can also be used to evaluate the effectiveness of a treatment plan by comparing pre- and post-treatment scores.

## 6.3 Future implications of the research

• Future research should aim for a more balanced gender distribution to ensure the findings are representative and applicable to both males and females with ASD.

• Further research on feeding issues, incorporating direct observations and utilizing larger sample sizes in children with ASD is necessary.

• Developing focused intervention approaches that address the important characteristics identified in this study is essential for improving the overall health of children with ASD.

• There is a need for more research to examine, taking cultural differences into account, the relationships between food selectivity and the growth of social and communication skills in people with ASD.

• Restricted food variety domain was identified by the research as a major concern by parents, highlighting the need for focused intervention initiatives in this area.

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# APPENDIX I

## **CONSENT FROM AUTHOUR**

	Request for translation of BAMBI questionnaire to Telugu language (spoken in India) 🕺 🖶 🗹								
	siri vandana «sirivandanat@gmail.com» . Sep 13, 2023, 12:55 PM 🙀 🕑 🦘 🚦 to LUKENS 🗸								
	Respected ma'am/sir, Am Siri Vandana, perusing my masters degree in Speech and language pathology in All India Institute of Speech and hearing, Mysore, India. I am very interested in feeding related studies in autistic children and i found BAMBI questionnaire to be sensitive for addressing feeding related issues in autistic children. I kindly request you to grand the consent to translate the Bambi questionnaire to my native language (Telugu) spoken in Southern part of India, as a part of my dissertation study under the guidance of Dr. Swapna N.								
	Kindly accept my request.								
	Thanking you, Yours sincerely, Siri Vandana , Msc -SLP All India Institute of Speech and Hearing,								
ଔ	Lukens, Colleen T I ILUKENS@chop.edu>								
From: siri vandana < <u>sirivandanat@gmail.com</u> > Sent: Wednesday, September 13, 2023 3:25 AM To: Lukens, Colleen T < <u>LUKENS@chop.edu</u> > Subject: [External]Request for translation of BAMBI questionnaire to Telugu language (spoken in India)									
	You don't often get email from <u>sirivandanat@gmail.com</u> . <u>Learn why this is important</u>								
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	One attachment • Scanned by Gmail ()								

## APPENDIX II BRIEF AUTISM MEALTIME BEHAVIOURAL INVENTORY-TELUGU

గత 6 నెలల నుండి భోజన సమయంలో మీ పాప/ బాబు యొక్క పరివర్తనలను లేదా గమనించిన విషయాలను కింది విధంగా సూచించండి.

/gata/ /a:ru/ /nelalu/ /nuAdi/ /b<sup>h</sup>o:dʒana/ /samajamlo/ /mi:/ /pa:pa/ /le:da:/ /ba:bu/ /jokka/ /parivartanalanu/ /le:da/ /gamaninchina/ /viʃayamlo/ /kiAdi/ /viɗAŋga/ /sutʃiiAtʃandi/

1. ఎప్పుడు 2. అరుదుగా 3. అప్పుడుఅప్పుడు. 4. తరుచుగా 5. దాదాపు ప్రతిసారి

1. /eppudu/ 2. /aruduga/ 3. /appudappudu/ 4. /tharutfuga/ 5. /da:da:pu//pratisa:ri/

	1.	తినేటప్పుడు, ఏడవటం/ అరవటం.	1	2	3	4	5
	/ṯine:tappudu/, /e:davatʌm/ /aravatʌm/		1	2	3	4	5
	2.	ఆహారం/ భోజనం నుండి మొహం (పక్కకు	1	2	3	4	5
ತಿಪ್ಪಿಷ	కీయటం.						
	/a:harʌ	m///bʰo:dʒanʌm//nuʌndi//mohʌm//pakkaku/ /t̪					
ippive:	jatʌm/						
	3. భోజం	నం చేసేటప్పుడు మధ్యలో లేచి వెళ్లిపోవటం.	1	2	3	4	5
	/bʰo:dʒa	anAm//tfe:se:tappudu//madhjalo//le:tfi//vellipo:vatAm/					
	4. ತಿನೆ	ఆహారాన్ని బయటకు ఉమ్మివేయటం/	1	2	3	4	5
తీసుకొనిరావటం.							
	/ ţIne/	//a:ha:ra:nni//bajataku//ummive:jatʌm//					
ţ]:suko	onira:vat	λm/					

5. భోజనం చే సేటప్పుడు కోపంగా/ చికాకుగా	1	2	3	4	5
ట్రవర్తించటం (తన్నటం, కొట్టడం, గీరటం లాంటివి.					
/bho:d3anAm//tfe:se:tappudu// ko:pAŋga//tfIka:kuga/					
/pravart_Intft.m/ / /kottad.m/, /gi:rat.m/ /la:.tivi/					
6. భోజన సమయంలో తనను తాను గాయపరచుకునేల	1	2	3	4	5
ట్రవర్ధించటం (కొట్టుకోవడం, కొరుక్యోవడం)					
/ bʰo:dʒana/ /samajʌmlo/ / t̪ananu/ / t̪a:nu/					
/ga:japarutʃukune:la/ /pravartiʌtʃatʌm/ (/kottuko:vadʌm/,					
/korukko:vadʌm/)					
7. భోజన సమయంలో అడ్డుపడడం/	1	2	3	4	5
తప్పించుకోవడం (ప్లేట్లు/ గ్లాసులు, ఆహారాన్ని నెళ్ళేయటం,					
విసిరివేయటం)					
/ bho:dʒana/ /samajʌmlo/ /addupadadʌm/ / t̪					
appintfuko:vadnm/ (/plettlu/, /gla:sulu/, /a:ha:ranni/					
/nettive:jatAm/, /visirive:jatAm/)					
8. భోజనం చూసినప్పుడు నోరు తెరవకుండా గట్టిగా	1	2	3	4	5
మూసి ఉంచటం.					
/bʰo:dʒanʌm/ /tʃu:sinappudu/ /no:ru/ /t̪eravakuʌda/ /gattiga/					
/mu:si/ /uʌtʃatʌm/					
9.భోజనం చేసే అలవాట్లను మార్చినప్పుడు	1	2	3	4	5
ఒప్పుకోకపోవటం (ఉదా., భోజన సమయం, కూర్చునే స్థలం,					
కూర్చునే విధానం).					
/bho:dʒanʌm/ /tʃe:se/ /alava:tlanu/ /ma:rtʃinappudu/					
/oppuko:kapo:vatʌm/ ( /u:dː/ /bhodʒana/ /samajʌm/, /ku:rtʃune/					
/sthalam/, /ku:rtfune/ /vidhanam/).					
10. కొత్త ఆహారాన్ని ట్రయత్నించడానికి	1	2	3	4	5
ఒప్పుకోకపోవటం.					

/ko'tʰa/ /a:hara:'ni/ /prajat\_niʌtʃada:niki/ /o'ppuko:kapo:vatʌm/

11. కొన్ని ఆహార పదార్గాలు ఇష్టం లేక					
తినకపోవటం (ఉదా., పచ్చి కూరగాయలు, పండ్లు)	1	2	3	4	5
/konni/ /a:ha:ra/ /pada:rt <sup>h</sup> a:lu/ /iʃtʌm/ /le:ka/ /t̪			-		-
I:suko:kapo:vatʌm/ (/ud̪a:/ /paˈtʃi/ /ku:raga:jalu/, /pʌdlu/)					
12. ఎక్కువగా నమిలి తినే ఆహారాన్ని					
తీసుకోకపోవటం (ఉదా., మెత్తగా లేదా జావలాగా ఉండే	1	2	3	4	5
పదార్థాలనే తీసుకోవడం).					
/ekkuvaga/ /namili/ /t̪ine/ /a:haranni/ /t̪I:sukokapo:vatʌm/					
(/uda:/ /me'thaga/ /le:dha/ /dʒa:avala:ga/ /uлde/ /padha:rtha:lane/					
/thi:sukovadAm/)					
13. భోజనం చేసే (పతి సారి ఒకే రకమైన	1	2	3	4	5
ఆహారం తీసుకోవడం ఇష్టం.					
/bho:dʒanʌm/ /tʃe:se/ /prathi:sa:ri/ /okei:/ /rakamaina/					
/a:harʌm/ /ṯ:suko:vadʌm/ /iʃtʌm/					
14. కరకర లాడే ఆహార పదార్థాలను	1	2	3	4	5
ఇష్టపడతారు (ఉదా., మురుకులు, చిరుతిండ్లు).					
/karakara//la:de//a:ha:ra//padhartha:lanu//ijtapadatha:ru/					
(uda: /murukulu/, /tʃiruthiʌndlu/)					
		_	_		
15. వివిధ రకాల ఆహార పదార్థాలను	1	2	3	4	5
ఇష్టపడకపోవటం.					
/vivivd <sup>h</sup> a//rakala//a:ha:ra//pad <sup>h</sup> a:rt <sup>h</sup> a:lanu/					
/iʃtapadaka.po:vatʌm/					
16. భోజన సమయంలో, ఆహారం ఓకే విధంగా	1	2	3	Λ	5
	1	Z	3	4	5
వడ్డించడాన్ని ఇష్టపడడం (ఉదా., ఒకే రంగు, ఒకే ఆకారం)					

	/bʰo:dʒan	na//samajʌmlo//a:ha:rʌm//okei://vidʰʌŋɡa/					
/va	-	//iʃtapadadʌm/ (/ud̪a://okeɪ://rʌgu/, /okeɪ:/					
/a:h	narʌm/)						
	17.	కేవలం తీపి పదార్థాలనే ఇష్టపడటం.	1	2	3	4	5
	/ke:valʌ	m/ /t̪:pi/ /pad̪a:rtʰa:lane/ /iʃtapadadʌm/					
	18.	ఒకే పద్దతిలో తాయారు చేసిన ఆహారాన్ని,	1	2	3	4	5
ಇ್	ప్లపడటం (ఉ	దా., పెరుగు అన్నం, నూనెలో వేయించిన					
ൠഁ	హారం).						
	/okei://j	paˈd̪at̪ilo/ /t̪aja:ru/ /tʃe:sina/ /a:ha:ra:nni/					
/i∫ta	apadatʌm/ (/u	ıda://perugu//annʌm/, /nu:nelo//ve:jiʌtʃina/					
/a:h	narʌm/ )						
	19.	తినే పదార్థాలలో కొన్ని వాసనలు	1	2	3	4	5
నల	మృతున్నాం	ు, మరికొన్ని నచ్చటం లేదు.					
	/ <u>t</u> ine://p	adartha:lalo//konni//va:sanalu//naˈtʃut̪unnaɪ/,					
/ma	ari/ /konni/ /n	atʃatʌm/ /le:du/					
	20.	కొన్ని రకాల ఆహార పదార్థాలని	1	2	3	4	5
ము	ుట్టుకోడానికి	లేదా తినడానికి ఇష్టం లేదు (ఉదా., తడిగా					
ස්ර	ండేవి, జిగురు	ත්රක්ටට කර					
	/konni/ /						
/le:	da:/ /t̪inada:n	iki/ /iʃtʌm/ /le:du/ (/uda:/ /tadiga/ /uʌdevi/,					
/dʒi	iguruga/ //uʌ	devi/)					