VALIDATION OF THE FEEDING/SWALLOWING IMPACT SURVEY-KANNADA ON CHILDREN WITH FEEDING DIFFICULTIES SECONDARY TO NEURODEVELOPMENTAL DISORDERS

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CERTIFICATE

This is to certify that this dissertation entitled **"Validation of the Feeding/Swallowing Impact Survey-Kannada (FS-IS-K) on Children with Feeding Difficulties Secondary to Neurodevelopmental Disorders"** is a bonafide work submitted as part of fulfilment of the degree of Master of Science (Speech Language Pathology) of the student with Registration Number P01II24S123011. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other university for the award of any other Diploma or Degree.

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CERTIFICATE

This is to certify that this dissertation entitled **"Validation of the Feeding/Swallowing Impact Survey-Kannada (FS-IS-K) on Children with Feeding Difficulties Secondary to Neurodevelopmental Disorders"** has been prepared under my supervision and guidance. It is also being certified that this dissertation has not been submitted earlier to any other university for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled **"Validation of the Feeding/Swallowing Impact Survey-Kannada (FS-IS-K) on Children with Feeding Difficulties Secondary to Neurodevelopmental Disorders"** is the result of my own study under the guidance of Dr. Swapna N, Professor of Speech Pathology, Centre for Swallowing Disorders, All India Institute of Speech and Hearing, Mysuru, and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

Mysuru

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Whatever happens,
happens for good

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF APPENDICES

List of frequently used abbreviations

- FSD – Feeding and Swallowing Disorders
- PFD- Pediatric Feeding Disorder
- NDDs- Neurodevelopmental Disorders
- ASD- Autism Spectrum Disorder
- ID- Intellectual Disability
- ADHD- Attention-Deficit/Hyperactivity Disorder
- CP- Cerebral Palsy
- DS- Down syndrome
- FS-IS - Feeding/Swallowing Impact Survey
- FS-IS-IK - Feeding/Swallowing Impact Survey- Kannada
- HRQoL - Health-Related Quality of Life
- QoL - Quality of Life
- ICC - Intraclass Correlation Coefficient

ABSTRACT

Feeding and swallowing difficulties are highly prevalent among children with neurodevelopmental disorders (NDDs), affecting up to 89% of children with Autism Spectrum Disorder (ASD) and 80% of those with Intellectual Disability (ID). These difficulties place significant physical, emotional, and social demands on caregivers, adversely affecting their health-related quality of life (HRQoL). While the Feeding/Swallowing Impact Survey-Kannada (FS-IS-K) has been validated for caregivers of children with cerebral palsy (CP), its applicability to caregivers of children with ASD and ID remain uninvestigated. This study aimed to validate the FS-IS-K among caregivers of children with Paediatric Feeding Disorder (PFD) secondary to ASD and ID, and to examine its reliability and clinical applicability beyond the CP population.

An analytical cross-sectional design was employed. Sixty primary caregivers of children aged 2–12 years diagnosed with PFD secondary to ASD (n = 26) or ID (n = 34) were recruited from AIISH, Mysuru, and special schools in Mysuru. The FS-IS-K was administered to assess feeding-specific caregiver HRQoL across three domains: daily activities, worry, and feeding difficulties. The Feeding Handicap Index (FHI; Physical and Functional domains) was also administered to assess feeding difficulty severity. Test–retest reliability was established in 20% of participants (n = 12) after two weeks using the Intraclass Correlation Coefficient (ICC). Statistical analyses included Mann–Whitney U tests, two-way MANOVA and ANOVA, and Pearson's and Spearman's correlation analyses.

The FS-IS-K demonstrated excellent test–retest reliability (total ICC = .995; subscale ICCs: .987–.984). The mean total FS-IS-K score was 53.93 (SD = 16.96), indicating moderate caregiver burden, with the ‘Daily Activities’ subscale showing the greatest impact. No significant differences in FS-IS-K scores were found across disorder type, age group, or

severity (all $p > .05$). In contrast, FHI scores differed significantly between groups, with the ID group showing greater feeding difficulty severity, particularly in the Physical domain ($p = .002$). In the ID group, significant positive correlations were observed between FHI scores and FS-IS-K scores ($r = .38–.51$) and between caregiver-reported severity of feeding difficulty and FS-IS-K scores ($\rho = .43–.53$). No significant correlations were observed in the ASD group.

It can be concluded that the FS-IS-K is a reliable and valid measure of feeding-specific caregiver HRQoL in Kannada-speaking caregivers of children with ASD and ID. Feeding-related caregiver burden was comparable across diagnostic groups and age ranges, suggesting that the FS-IS-K captures a broadly consistent burden profile independent of diagnosis. The disorder-specific pattern of correlations between feeding severity and caregiver HRQoL highlights the distinct nature of feeding difficulties in ASD versus ID and underscores the importance of population-sensitive clinical assessment. These findings extend the clinical utility of the FS-IS-K beyond CP, supporting its use as a routine, family-centred outcome measure in paediatric feeding services.

Chapter 1

Introduction

Neurodevelopmental disorders (NDDs) are a heterogeneous group of conditions characterised by impairments in cognitive, behavioural, motor, sensory, communication, and adaptive functioning that emerge during the developmental period (American Psychiatric Association, 2013). NDDs consist of intellectual disability (ID), communication disorders, autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), specific learning disorders, and motor disorders. Children with these conditions often have feeding and swallowing difficulties (Andrew & Sullivan, 2010a; Manikam & Perman, 2000; Reilly et al., 1996; Sullivan et al., 2000), which can have negative consequences on their nutrition, growth, respiratory health, participation in daily life, and psychosocial functioning (Goday et al., 2019; Lefton-Greif, 2008; Reilly et al., 1996).

Feeding and swallowing are complex developmental processes that require coordinated interactions between sensory, motor, behavioural, cognitive, and psychosocial systems (Delaney & Arvedson, 2008; Goday et al., 2019; Stevenson & Allaire, 1991). Disruption in any of these underlying systems can result in feeding and swallowing disorders (FSDs), which are common in paediatric populations and are particularly common in children with chronic medical or neurodevelopmental conditions (Andrew & Sullivan, 2010a; Rogers & Arvedson, 2005). Feeding experiences are not only a source of nutritional sustenance, but are also key contributors to the development of communication, emotional bonding, social interaction, adaptive functioning and the development of independence in children (Delaney & Arvedson, 2008; Rybak, 2015; Smithard, 2015).

FSDs are especially prevalent among premature infants and children with complex medical needs (Kakodkar & Schroeder, 2013), and are associated with adverse consequences

such as malnutrition, dehydration, recurrent respiratory illnesses, and reduced quality of life (QoL; Rogers & Arvedson, 2005; Vesey, 2013). Feeding and swallowing difficulties have been estimated to occur in 25–45% of typically developing children and 33–80% of children with developmental disabilities (Lefton-Greif, 2008). NDDs are considered one of the major risk factors for feeding and swallowing difficulties, as the associated deficits in cognition, sensory processing, motor functioning, and behaviour can directly affect safe and efficient feeding.

Research shows that almost 80% of children with neurodevelopmental conditions experience some kind of feeding problem (Manikam & Perman, 2000). High prevalence has been reported in children with ASD (76%; Nygren et al., 2021), ID (80%; Palmer et al., 1975), and CP (80%; Esmaeili et al., 2024). Common feeding-related concerns reported in these children include food selectivity, oral-motor dysfunction, prolonged feeding duration, feeding dependency, and disruptive mealtime behaviours (Reilly et al., 1996; Sullivan et al., 2000).

In the Indian context, Crasta et al. (2014), in a clinical study, observed feeding problems in 61% of children with ASD and 46.4% of children with ID, with greater severity in children with ASD. The study also showed a strong association between sensory processing impairments and feeding difficulties. Similarly, in another study of 79 children with NDDs aged 2–12 years, Manikandan et al. (2023) revealed that more than half of the participants had deficits in feeding skills and behavioural feeding problems that were significantly associated with oral-motor dysfunction. These findings highlight the complex multifactorial aetiology of feeding and swallowing difficulties in children with NDDs and the importance of early identification and comprehensive multidisciplinary management. The manifestations of feeding and swallowing difficulties may vary according to the underlying neurodevelopmental condition and associated impairments. Common feeding difficulties among children with developmental delays include uncoordinated sucking, immature biting and chewing, poor propulsion of bolus, primitive or weak oral reflexes, delayed swallow trigger, absent swallow

reflex, laryngeal penetration and nasopharyngeal regurgitation (Dodrill & Gosa, 2015). These difficulties can have implications for the safety and efficiency of feeding, with consequences for nutritional intake, growth and health.

Feeding and swallowing difficulties may present differently across various NDDs. Research reports that children with ASD experience more frequent feeding difficulties and consume a more restricted variety of foods than children without ASD, including both typically developing peers and those with other developmental disabilities (Bandini et al., 2010; Matson et al., 1991; Nadon et al., 2011). The feeding difficulties commonly observed in children with ASD include food selectivity (Cermak et al., 2010), food refusal (Schreck et al., 2004), and disruptive mealtime behaviours (Provost et al., 2010). A review of 44 studies confirmed that these problems are wide-ranging, encompassing limited dietary variety, food neophobia, texture aversions, and nutritional risk (Marshall et al., 2014). Beyond food-related behaviours, oral-motor difficulties have also been documented, including challenges with straw drinking due to inadequate lip seal, difficulty sustaining continuous sips, and aversive responses to tactile input, likely related to impaired oral-motor control, oral sensory sensitivities, or hyper-gag responses (Bebayal et al., 2024; Panerai et al., 2020).

Feeding-related difficulties have also been documented in children with ID. These include tantrums, unusual food habits, multiple food dislikes, texture selectivity, delays or difficulties in chewing, sucking or swallowing, delays in self-feeding, pica, excessive overeating, inadequate intake leading to malnutrition, and rumination (Linscheid, 1983; Rezaei et al., 2011). In addition to these behavioural concerns, oral-motor deficits have also been documented. These children show inadequate rotatory chewing patterns, poor control and manipulation of the bolus and limited tongue lateralisation (İslamoğlu et al., 2024; Rezaei et al., 2011). In children with Down syndrome (DS), who represent a distinct subgroup within the ID population, oral-motor feeding challenges are often more pronounced due to syndrome-

specific craniofacial, neuromotor, and anatomical characteristics (Anil et al., 2019). These children experience feeding problems predominantly in the oral phase, followed by the pharyngeal and esophageal phases, predominantly for solids than liquids (Malavika, 2015) often due to low muscle tone and limited oral muscle strength and mobility, leading to poor suck and swallow coordination, weak lip closure, tongue protrusion, immature chewing pattern, poor bolus control and manipulation, limited lateralization of tongue and tongue thrusting (Malavika, 2015; Pilcher, 1998). Looking beyond DS to the broader ID population, an Iranian study of 144 individuals with intellectual disabilities (including Down syndrome, autism, CP and other disabilities) found that almost all of the participants had feeding problems, and some were at risk of aspiration (Rezaei et al., 2011).

Age-inadequate feeding abilities can result in disrupted mealtimes, undernutrition, constipation, growth failure, aspiration risks, and frequent hospitalizations due to aspiration pneumonia (Andrew & Sullivan, 2010b; Sullivan et al., 2000). In children with NDDs, complications such as malnutrition or risk of malnutrition affect up to 80% of clinical cases (Grot et al., 2024), with consequences for physical growth, socioemotional development, and overall QoL (Bebayal et al., 2024).

The impact of the feeding difficulties extends beyond the child to caregivers and family dynamics. Caregivers of children with feeding and swallowing problems frequently report emotional discomfort, compromised well-being, and strained child-caregiver interactions (Arvedson et al., 2020; Greer et al., 2007). They have been reported to experience stress, anxiety, low mood, and depression (Andrew & Sullivan, 2010a; Azios, 2016), and often feel tired and unwell as a result of caregiving demands (Reis et al., 2020). Many caregivers feel unprepared for the complex demands of managing feeding difficulties or blame themselves for their child's problems, which can negatively affect their self-efficacy, parenting confidence, and self-esteem (Craig et al., 2003; Greer et al., 2007; Rama et al., 2022; Sherman et al., 2019).

Mealtime challenges, including food refusal, aversion, and externalising behaviours such as aggressiveness, are significant sources of caregiver stress, while internalising behaviours in the child, such as anxiety or low mood, suggest dysfunctional interactions (Silverman et al., 2021). Although strategies such as dietary modifications, use of appropriate utensils, repositioning, and pacing can be helpful, implementing these consistently is demanding, and higher caregiver stress is associated with less effective execution of such strategies (Crist et al., 1994; Harding & Cockerill, 2015). Caregivers also often face restricted access to adequate support, manage conflicting family viewpoints over feeding approaches, and must adapt continuously to their child's food preferences (Yap et al., 2025). Furthermore, caregivers must learn specific skills to manage the feeding difficulties at home, which further increases the caregiving burden (Lutz, 2012).

At a broader level, caregivers frequently report disruptions to family routines, reduced participation in social activities, and concerns about the impact on work, leisure, and emotional support (Hatzmann et al., 2009; Lefton-Greif et al., 2014; Rama et al., 2022). Perceptions of increased caregiving difficulty have also been positively associated with maternal depression (Davis et al., 2003; Silver et al., 1998). Greater feeding difficulty severity has been associated with poorer caregiver QoL and increased caregiver burden (Lefton-Greif et al., 2014), and these difficulties contribute to the caregiver's overall burden, social isolation, and stress (Brehaut et al., 2004; Ones et al., 2005).

The QoL of caregivers has been researched substantially in several NDDs (Carona et al., 2014; Lach et al., 2009; Reis et al., 2020). There are many freely available and easily accessible tools to detect and quantify caregiver QoL. However, although caregiver QoL has received more attention in recent years, only a few studies have specifically examined the QoL of caregivers of children with feeding issues.

Considering the frequent co-occurrence of feeding difficulties in children with NDDs, understanding the experience of caregivers is of particular importance (Lefton-Greif et al., 2014; Rogers & Arvedson, 2005). Physical limitations, sensory sensitivities, and cognitive deficits associated with NDDs may further compound the feeding difficulties and make appropriate food and nutrition management more challenging. In response to these challenges, caregivers will need to provide constant support that is often time-consuming and demanding, contributing to increased stress and emotional strain (Lefton-Greif et al., 2014; Rama et al., 2022). When caregiver QoL is compromised, the effective management of feeding difficulties of the child is also likely to be adversely affected, creating a bidirectional relationship between caregiver well-being and child outcomes. Understanding factors that influence caregiver QoL may therefore help healthcare practitioners provide the right type of support and care. Timely intervention and early detection of caregiver QoL problems specific to FSD can result in better outcomes and improved QoL for both children and caregivers.

The increasing awareness of caregiver burden and QoL concerns has made the need for standardised measures of assessment apparent. The development of the Feeding/Swallowing Impact Survey (FS-IS) screening tool (Lefton-Greif et al., 2014) has the potential to enhance understanding and meet the needs of the caregivers of children with feeding deficits. It is a tool to evaluate the health-related quality of life (HRQoL) of caregivers of children with feeding and swallowing difficulties. The 18-item questionnaire is divided into three key areas: daily activities, worry, and feeding difficulty. A 5-point Likert scale is used, where a score of "1" indicates "never" and "5" indicates "almost always," with higher scores signifying a poorer HRQoL of the caregiver. This tool has been translated and validated in a number of languages since it was first created in English. These languages include Turkish (Serel Arslan et al., 2018), South African (Bestenbier, 2021), Brazilian Portuguese (Rama et al., 2022), Persian (Mokhlesin et al., 2024), and Italian (Baffi et al., 2025). Considering the unique aspects of

Indian families, urban–rural distribution, linguistic diversity, cultural practices, food habits, and varied educational and socioeconomic statuses, there was a clear need to adapt and validate the FS-IS tool for the Indian context. In addition, the absence of a screening tool to evaluate caregiver HRQoL further necessitated the adaptation, translation, and validation of the FS-IS into Kannada (Mathew, 2024). The Feeding/Swallowing Impact Survey-Kannada (FS-IS-K) retained the original 18-item structure and was validated with 60 children with CP in the age range of 2-18 years. The study reported an average FS-IS-K score of 2.54, reflecting a decline in caregiver QoL. Caregivers expressed greatest concerns about leaving their child with others for feeding, difficulties in making family plans or eating out, negative reactions from others, worries about whether their child would ever eat or drink like typically developing children, and conflicting guidance from family members and professionals.

The tool demonstrated strong psychometric properties, with good internal consistency (0.99) and high test–retest reliability (0.89). Average (moderate) positive correlations were established between FS-IS-K and both the Kannada version of the 'Burden of Persons with Aphasia on Caregivers' (Swati, 2008) and the Feeding Handicap Index (FHI; Shabnam & Swapna, 2023), supporting its validity. While caregiver age, education, socioeconomic status, and other care-recipient variables showed no significant associations, the child's age was found to be a significant contributor to caregiver burden.

Justification for the study

The literature revealed that currently in the Indian context, there is a tool to assess the HRQoL of caregivers of children with feeding difficulties in Kannada developed by Mathew (2024), which is the Feeding/Swallowing Impact Survey-Kannada (FS-IS-K). However, this tool has been validated only on children with CP who have feeding difficulties, which limits its utility to caregivers of children with other NDDs. The literature, however, shows that children with other NDDs also exhibit feeding and swallowing difficulties. These difficulties

could be because of sensory issues, as in children with ASD, due to poor tone as in DS, due to behavioural issues as in children with ID, etc. Therefore, it is equally important to assess and document the HRQoL of caregivers of these children. Such insights will provide valuable guidance to speech-language pathologists when managing feeding and swallowing problems in children with diverse neurodevelopmental conditions. Clinicians will also gain awareness of the extent to which feeding problems affect caregivers across multiple life domains. The psychometric properties of the FS-IS-K may be strengthened through validation across a broader range of NDDs. Expanding validation to other NDDs would enhance the tool's generalizability to better capture the diversity of caregiver experiences and support more inclusive, family-centred care across paediatric feeding setups. Since the FS-IS-K has so far been validated only in children with CP (Mathew, 2024), the present study aimed to extend its utility by validating the tool in children with other NDDs (excluding CP).

Aim of the Study

The study aimed to validate FS-IS-K on caregivers of children with feeding difficulties secondary to neurodevelopmental disorders (ASD and ID), in order to determine its validity, reliability, and applicability beyond the population with CP.

Primary Objectives:

1. To clinically validate the FS-IS-K on caregivers of children with Pediatric Feeding Disorder secondary to ASD and ID.
2. To establish the test-retest reliability of the FS-IS-K among caregivers of children with ASD and ID.

Secondary Objectives:

- To investigate the relationship between disorder severity (mild and moderate) and FS-IS-K scores among caregivers of children with ASD and ID.
- To compare FS-IS-K scores between caregivers of children with ASD and caregivers of children with ID, and between caregivers of younger children (2–6 years) and older children (6–12 years).
- To compare FHI scores (Physical domain, Functional domain, and total scores) between children with ASD and ID and across younger and older age groups (2-6 vs. 6-12 years)
- To assess the correlation between total FHI scores and FS-IS-K scores in both the disorder groups.
- To assess the correlation between caregiver-reported severity of feeding difficulties derived through FHI and FS-IS-K scores in both the disorder groups.

Hypotheses of the study

The null hypotheses for the objectives are given below:

H_{01}: There is no significant difference in FS-IS-K scores between caregivers of children with mild and moderate severity of ASD and ID.

H_{02}: There is no significant difference in FS-IS-K scores between caregivers of children with ASD and caregivers of children with ID, or between caregivers of younger children (2–6 years) and caregivers of older children (6–12 years).

H_{03}: There is no significant difference in FHI scores (Physical domain, Functional domain, and total scores) between children with ASD and ID and between younger (2–6 years) and older children (6–12 years).

H_{04}: There is no significant relationship between total FHI scores and FS-IS-K scores in the ASD and ID group.

H_{05}: There is no significant relationship between caregiver-reported severity of feeding difficulties derived through FHI and FS-IS-K scores in the ASD and ID groups.

Chapter 2

Review of Literature

Feeding is a sensorimotor activity that has been refined with age, reflecting the increasing maturity of the central nervous system. As time progresses, anatomical structures develop and shift in position, progressively shaping the functional capacities necessary for safe and effective feeding (Stevenson & Allaire, 1991). These functional capacities encompass respiratory function for breathing, oral function for food sensitivity, pharyngeal function for safeguarding the airway, and the gastrointestinal system for food digestion (Beecher & Alexander, 2004). Together, these systems underpin the child's capacity to perform a highly complex activity that requires both the physiological act of eating and behavioural control. According to Arvedson & Brodsky (2002), feeding is the process of accepting, manipulating, and preparing food and liquids for swallowing. Understanding how children's feeding skills evolve is essential. As these skills develop, food consistencies and the feeding techniques also evolve (Arvedson et al., 2020; Pridham, 1990). While feeding encompasses the broader process of accepting and managing food and liquids, swallowing (or deglutition) represents a critical component of feeding and refers specifically to the transport of a bolus from the mouth to the stomach.

Swallowing is a sophisticated sensorimotor act requiring bilateral activation and inhibition of the muscles of the lips, tongue, pharynx, larynx, and oesophagus (Ertekin & Aydogdu, 2003). This process depends on the precise coordination of movements that transfer food from the mouth to the stomach (Arvedson et al., 2020; Miller, 1986). It contrasts with feeding as it is predominantly a neuromuscular function that depends upon both voluntary and involuntary nerve control. The coordination of swallowing involves a central pattern-generating mechanism in the brainstem (Logemann, 1998). During swallowing, precise timing is required at all phases for a safe and efficient swallow (Nishino, 2013).

Given this complex neuromuscular coordination, swallowing is typically described as a sequence of interrelated phases. According to Logemann (1998), swallowing is a sequence of events coordinated in a manner that propels the bolus from the mouth to the stomach while protecting the airway. Any alteration in this process may cause penetration or aspiration, particularly in children. The swallowing mechanism consists of four phases: The oral preparatory phase, the oral transport phase, the pharyngeal phase and the oesophageal phase (Logemann, 1998) and the distinction between these phases depends upon the location of the bolus (Dodds et al., 1990; Logemann, 1998; Matsuo & Palmer, 2008).

During the oral preparatory phase, the food is manipulated, combined with saliva, and chewed to form a cohesive bolus (Dodds et al., 1990). While coordinated movements of the tongue, jaw, and cheeks position the bolus correctly, adequate lip closure prevents anterior spillage. During the oral transport phase, the tongue tip elevates to the alveolar ridge and the bolus is positioned behind this without spillage (Dodds et al., 1990). At this point, the soft palate also elevates to contact the posterior pharyngeal wall, thereby preventing nasal regurgitation (Dodds et al., 1990). During the pharyngeal phase, the larynx elevates, the false vocal folds and true vocal folds contract, and the inversion of the epiglottis occurs (Logemann, 1998). Breathing ceases temporarily to protect the airway. Pharyngeal constrictors move the bolus downward while the upper oesophageal sphincter opens (Arvedson et al., 2020). During the oesophageal phase, the pharyngo-oesophageal sphincter opens, and the food goes through the oesophagus into the stomach. These actions during the process of deglutition occur in quick succession (Arvedson & Brodsky, 1993). Although these physiological events occur rapidly and largely automatically, feeding and swallowing have significance that extends beyond the safe transport of food and liquids.

Feeding and swallowing serve purposes beyond meeting nutritional needs and play a vital role in a child's social, emotional, sensorimotor, and communication development.

Mealtimes are one of the most constant and primary settings for social interactions, during which infants and caregivers engage in eye contact, take turns, vocalise, and share attention, which form the building blocks of early communication (Morris & Klein, 2000; Rybak, 2015). Such predictable and structured feeding routines promote emotional bonding, attachment and self-regulation (Pridham, 1990).

From a developmental aspect, feeding experiences are critical in terms of sensorimotor integration. Sensory stimulation of oral structures during feeding promotes maturation of oral motor patterns and facilitates proper cortical mapping of sensory and motor pathways (Arvedson & Brodsky, 2002). Healthy motor learning is based on positive feeding experiences and helps develop speech and non-speech oral motor skills (Delaney & Arvedson, 2008).

Research highlights that feeding interactions provide rich opportunities for communication development. Rezaei et al. (2011) observed that infants who had positive feeding experiences had an earlier vocal development and social responsiveness. Feeding times are thought to be the most natural times for children to express their needs, such as hunger, satiety or liking, which are reinforced by caregiver responses, and together they build communication abilities.

Feeding also supports the development of independence and self-regulation. The progression from dependent feeding to self-feeding involves developing modulation of food intake and adjustment to social environments, enhancing children's autonomy and self-efficacy (Smithard, 2015). Given the multifaceted role of feeding and swallowing in supporting nutrition, growth, sensorimotor development, communication, and psychosocial well-being, understanding the typical developmental progression of these skills is essential. Knowledge of normal feeding and swallowing development provides a framework for identifying deviations

that may place children at risk for feeding and swallowing difficulties. Accordingly, it is important to examine how feeding skills develop across childhood.

Development of Feeding and Swallowing in Children

Feeding and swallowing development is an intricate, maturational process that begins prenatally and persists into childhood. This process requires maturation of the brain, posture control, oral motor abilities, and integrated sensory inputs, all of which support increasingly safe and efficient feeding as coordination develops with age. Swallowing patterns are apparent before birth, with foetal swallowing being detected as early as the first trimester (Miller et al., 2003). These early swallowing movements facilitate oropharyngeal maturation and prepare the infant for postnatal feeding. Feeding at birth is mainly reflexive and guided by brainstem activity (Maynard et al., 2020). Infants at birth suckle by using a primitive swallow pattern involving horizontal movements that promote milk intake, while maintaining nasal breathing (Maynard et al., 2020).

From birth to four months, suckling remains dominant and feeding behaviours are largely reflexive (Arvedson & Lefton-Greif, 1996). At two to three months, there is an onset of increased stability in the jaw, lip closure, and control over the neck, as there is more neuromotor maturation (Arvedson et al., 2020).

During the period between four and six months, the infant progresses from suckling to sucking, which involves vertical movements of the tongue and greater participation of the jaw (Arvedson et al., 2020). This period marks the introduction of mashed foods and represents a critical phase in the development of feeding skills (Morris & Klein, 2000).

By six months, infants demonstrate multidirectional tongue movements, sustained lip closure, and early chewing behaviours. Vertical 'munching' type jaw motions occur from the age of six to nine months, thereby forming the basis for rotatory chew (Arvedson & Lefton-

Greif, 1996; Gisel, 1988). Oral exploration increases during this period, and around eight months, improved coordination of sucking and swallowing supports efficient nutrition (Pridham, 1990). As maturation continues, feeding skills become increasingly refined.

At ten to twelve months, coordination between the lip, tongue, and jaw enhances and becomes more refined. Between twelve and eighteen months, lateral tongue movements become more established, and improved coordination of swallowing and breathing reduces the risk of aspiration (Arvedson et al., 2020). Rotatory chewing usually emerges around twenty-four months of age, enabling proper handling of texture (Gisel, 1988). By twenty-four to thirty-six months, feeding patterns continue to mature and become more adult-like, marked by sustained lip closure and circular jaw movements (Arvedson et al., 2020).

Any delays or deviations in the typical development of feeding and swallowing skills may increase a child's risk for feeding and swallowing disorders (FSDs). The failure to achieve expected milestones such as effective suck-swallow coordination, progression to textured foods, or the development of mature chewing patterns within the anticipated timeframes can lead to children experiencing trouble with safe, efficient, or adequate oral intake (Arvedson & Brodsky, 2002). Neurological immaturity, prematurity, structural anomalies, or negative early feeding experiences can also disrupt the development of feeding skills (Morris & Klein, 2000). If left unaddressed, these difficulties can result in poor growth, nutritional deficiencies, caregiver stress, and long-term aversion to eating. Consequently, children may develop feeding and swallowing disorders that vary in severity and underlying aetiology. Therefore, an understanding of typical feeding and swallowing development is essential for recognising and identifying FSDs in children.

Feeding and Swallowing Disorders

When the typical development of feeding and swallowing is disrupted, children may

experience FSDs that impair the safe and efficient ingestion of nutrition and hydration (Goday et al., 2019). These impairments may arise from structural, neurological, sensory, behavioural, or psychosocial dysfunctions (Arvedson & Brodsky, 2002).

Feeding difficulties are conceptualised in a broad sense as the problems concerning the acceptance of food, age-appropriate feeding skills, intake patterns, or mealtime behaviours, regardless of the underlying medical or developmental aetiology. This conceptualisation is consistent with the classification of paediatric feeding problems proposed by Kerzner et al. (2015), which includes functional behaviours like limited appetite, food selectivity, and fear of feeding, rather than isolated physiological impairments.

On the other hand, swallowing disorders (dysphagia) can be defined as impairments in the swallowing pathway and the effects these impairments may have on the swallowing mechanism. Some of the common clinical signs of dysphagia include choking, coughing, delayed swallow start, aspiration, nasal regurgitation, and poor bolus transport through the oral, pharyngeal, or oesophageal phases of swallowing (Dodrill & Gosa, 2015; Logemann, 1998). Dysphagia may occur in one or more phases and can cause severe consequences in terms of malnutrition and psychosocial effects (Arvedson & Brodsky, 2002; Logemann, 1998).

Research indicates that feeding and swallowing problems are prevalent across the paediatric population, not only among children with medical or developmental conditions but also among typically developing children (Gisel, 2008; Laud et al., 2009; Voulgarakis & Forte, 2015). Epidemiological studies suggest that feeding problems are encountered by about 20–30% of children who are typically developing, with the highest rates found in infants and toddlers (Kerzner et al., 2015; Manikam & Perman, 2000). Common manifestations include food refusal, prolonged mealtimes, highly restricted dietary variety, and reduced appetite. When compared to the general paediatric population, the prevalence of feeding and swallowing disorders is significantly higher among high-risk paediatric populations, which include

children with neurodevelopmental disorders (NDDs), prematurity, genetic syndromes, and complex medical conditions (Arvedson & Brodsky, 2002; Dodrill & Gosa, 2015). Given the heterogeneous nature of feeding difficulties, efforts have been made to establish a comprehensive diagnostic framework that captures the multidimensional aspects of paediatric feeding problems.

Pediatric Feeding Disorders

Within the broader category of feeding and swallowing disorders, Paediatric Feeding Disorders (PFDs) are increasingly recognised as complex conditions encompassing one or more domains, including medical, nutritional, feeding skill, and psychosocial factors (Goday et al., 2019). Goday et al. (2019) state that the feeding difficulties have to be present for at least two weeks to meet the diagnostic criteria for PFD. Feeding difficulties lasting for less than two weeks are considered transient and do not meet the diagnostic criteria for PFD. This distinction is important clinically because transient issues associated with paediatric feeding may be seen with acute illnesses, teething, and/or environmental adjustments and often resolve without long-term intervention.

Goday et al. (2019) also classified PFD on the basis of duration and clinical significance. Acute PFD is a feeding disorder that continues for a period of two weeks to less than three months. PFD is classified as chronic when it persists for longer than three months. Children with chronic PFD may exhibit more severe consequences, including stunted growth, micronutrient deficiencies, and persistent feeding difficulties. PFD can happen in any child, but some groups of children are at greater risk than others. Children with NDD are at increased risk of persistent feeding problems due to a complex interaction of neurological, sensory, motor, cognitive and behavioural factors that influence feeding development.

Paediatric Feeding Difficulties in Children with NDDs

NDDs include intellectual disability (ID), autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), communication disorders, specific learning disorders and motor disorders. The presence of NDDs is one of the major factors for PFD. The literature suggests that children with neurodevelopmental impairments are much more likely to present with persistent feeding and swallowing problems than children without NDDs (Lefton-Greif, 2008; Rogers & Arvedson, 2005). This increased vulnerability is a function of the interplay of neurological immaturity, poor motor planning, sensory processing differences, cognitive limitation, and behaviour regulation difficulties commonly associated with NDDs.

Prevalence studies have shown a higher incidence in children with developmental disabilities, with estimates varying from 13% to 80% (Lefton-Greif, 2008; Rohil et al., 2025). Globally, feeding difficulties affect approximately 33–80% of children with disabilities and are often associated with undernutrition, growth faltering, and increased caregiver stress (Klein et al., 2023).

Evidence from the Indian context supports these findings. In a cross-sectional study on feeding challenges in children with NDDs, Manikandan et al. (2023) examined 79 children (aged 2-12 years) and found that over half of the participants had serious behavioural issues and feeding-related skill deficiencies. Another study by Verma et al. (2025), involving 150 children with developmental disabilities, reported differences in pediatric feeding outcomes across disorders. The highest behavioral pediatric feeding problem scores were observed in children with ID (M = 66.62, SD = 10.95), followed by ADHD (M = 63.29, SD = 11.75), ASD (M = 58.59, SD = 11.14), specific language disability (M = 57.11, SD = 11.57), CP (M = 53.81, SD = 13.35), and Down's syndrome (M = 54.33, SD = 10.37).

Among neurodevelopmental conditions, children with cerebral palsy (CP) are particularly vulnerable to feeding and swallowing difficulties because of impairments in motor control, posture, and oral-motor function. Feeding difficulties are frequently encountered among children with CP, with estimates suggesting that from 30% to 80% of individuals with disabilities experience challenges (Aponte & Romanczyk, 2016). Reilly et al. (1996) investigated 49 children with CP aged 12–72 months and found that sucking difficulties (57%) and swallowing difficulties (38%) were prevalent in the first year of life. Over 90% demonstrated clinically severe oral motor impairment, and 60% had severe eating difficulties even before a CP diagnosis was established. Andrew & Sullivan (2010b) reported that 78% of 55 children with CP experienced feeding problems.

A 2025 South Asian study of 226 children with CP reported a very high burden of malnutrition linked to feeding difficulties, with around 50% of children under five years experiencing moderate or severe acute malnutrition, increasing to 59% among those with the most severe motor impairment (GMFCS level V) (Dalpatadu et al., 2025).

While neuromotor dysfunction, abnormalities in sensory processing, and poor behavioural regulation are common risk factors among NDDs, feeding issues present differently depending on the diagnosis (Kerzner et al., 2015; Lefton-Greif, 2008). Due to delayed oral-motor skill acquisition and decreased adaptive functioning, children with intellectual disabilities frequently exhibit feeding difficulties (Gisel, 2008). On the other hand, food selectivity, strict mealtime behaviours, and sensory-based food aversions are more commonly associated with feeding issues in autism spectrum disorder (Bandini et al., 2010; Laud et al., 2009). Feeding problems in children with ADHD are often associated with impulsivity, inattention, poor self-regulation and irregular eating patterns (Kerzner et al., 2015). These differences highlight the need for condition-specific evaluation and treatment of children with PFD. Among the various NDDs, feeding difficulties have also been extensively studied in

children with ASD and ID, owing to their high prevalence and significant impact on nutritional status, mealtime participation, and caregiver well-being.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is characterised by deficits in social communication and social interactions, as well as the presence of restricted repetitive and stereotyped patterns of behaviour, interests, and activities (American Psychiatric Association, 2013). These features may be observable around the age of three years and may persist throughout life (Kamp-Becker et al., 2010).

Studies have indicated that 46% to 89% of children diagnosed with ASD had comorbid feeding issues (Bandini et al., 2010; Ledford & Gast, 2006; Raiten & Massaro, 1986; Schmitt et al., 2008; Seiverling et al., 2011). A comprehensive meta-analysis of 17 controlled studies found that children with ASD were over five times more likely to show feeding problems than non-autistic children, which well illustrates the strong association between ASD and feeding dysfunction (Leader et al., 2020).

Cross-sectional studies indicate that the prevalence of feeding issues in the population of children with ASD is reported to be 73% (Visvalingam & Sivanesom, 2024), with rates reaching 76% in preschool populations. In addition, around 28% of children with ASD meet criteria for avoidant/restrictive food intake disorder (ARFID, Nygren et al., 2021). In a study of 396 preschool children with ASD, most were found to have feeding difficulties rated as low and stable (26.3%) or moderate and declining over time (38.9%). A third group (26.5%) showed high levels of feeding problems as preschoolers that declined to the average range by school age. While some children demonstrated improvement over time, others continued to show high levels of feeding dysfunction, highlighting the heterogeneity and persistence of feeding issues in ASD (Peverill et al., 2019).

In the Indian context, a comparative study of children aged 3–10 years found that feeding problems affected 61% of children with autism, with greater severity observed in younger children, while no significant gender differences were observed (Crasta et al., 2014). Another comparative study showed 79% of ASD parents reported feeding concerns with higher Children's Eating Behaviour Inventory (Archer et al., 1991) scores and more problems like food selectivity (Malhi et al., 2017).

Children with ASD commonly exhibit behaviours such as food selectivity, mouthing of non-food items, resistance to novel foods, texture-based food restriction, gagging, refusal to sit at the table, and throwing or discarding food (Provost et al., 2010). Food selectivity is the most frequently reported feeding issue in children with ASD. It is characterised by a restricted range of accepted foods, often based on sensory attributes such as texture, colour, taste, temperature, or presentation. Several studies revealed that children with ASD have a clear preference for carbohydrate-rich foods, while being averse to fruits, vegetables, and proteins (Ahearn et al., 2001; Schreck et al., 2004; Williams et al., 2005). Sharp et al. (2013) reported that the majority of ASD children exhibited selective food acceptance when they were observed during structured meals, with vegetables being the most frequently rejected category.

Field et al. (2003) found that 62% of autistic children showed food selectivity according to food type, and Williams et al. (2000) found that 69% of children with ASD showed food neophobia, whereby they had fear and avoidance of novel food. Moreover, nearly half of these children exhibited stereotyped behaviours that led to disruption in the process of eating, thereby reducing food variety.

Children with ASD may exhibit food refusal in the form of complete food group avoidance, food expulsion, refusal to open the mouth, or outright rejection of foods. According to Schreck et al. (2004), food refusal in ASD is frequently associated with hallmark features of

autism, i.e., rigidity and resistance to change. When coupled with restricted dietary repertoires, this trend can severely reduce calorie intake and raise caregiver stress. Significantly, the development and persistence of food refusal behaviours in this population are often linked to variations in sensory processing.

Research has found that autistic children's feeding difficulties may be related to their sensory profiles (Boudjarane et al., 2017; Page et al., 2022). Atypical sensory processing, such as hypersensitivity to taste, texture, smell and visual presentation of food, plays a key role in feeding behaviours among children with ASD. Children with sensory sensitivities may be unwilling to eat foods with a certain taste, smell, or texture, avoid mixed textures, and show distress during mealtime (Baraskewich et al., 2021). These sensory processing difficulties are thought to be related to core ASD traits such as reduced novelty acceptance and preference for sameness, and have been found to correlate with feeding challenges (Baraskewich et al., 2021). This may lead to mealtimes being a stressful experience for the child and the family, leading to a greater preference for restricted eating habits.

Disruptive mealtime behaviours are also frequently observed and include crying, aggression, throwing food, leaving the table, or engaging in repetitive behaviours during meals (Provost et al., 2010; Rogers et al., 2012; Twachtman-Reilly et al., 2008). Visvalingam and Sivanesom (2024) reported pushing food away (77.1%), head turning (72.8%), crying (70%), leaving the table (58.5%), screaming (45.7%), negative statements (44.2%), throwing things (41.4%), disruptive behaviours (28.5%), and aggression (22.8%) as some of the disruptive mealtime behaviours.

There is a significant correlation between increased food selectivity and disruptive feeding behaviours that occur more often (Sharp et al., 2013). Disruptive feeding behaviours

not only negatively affect feeding efficiency but also reduce opportunities for positive social interaction during mealtimes, which is vital for developmental learning.

Intellectual Disability

Intellectual Disability (ID), previously termed mental retardation, is characterised by significant deficits in intellectual functioning and adaptive behaviour across conceptual, social, and practical domains, with onset during the developmental period. It is typically diagnosed when intellectual functioning is approximately two standard deviations below the mean, i.e. IQ around 70 or below (American Psychiatric Association, 2013).

Feeding difficulties are highly prevalent in children with ID and increase in frequency and severity with greater levels of intellectual impairment (Sharp et al., 2013). Early studies indicated that around 30% of children with ID had feeding problems (Gouge & Ekvall, 1975; Palmer et al., 1975). Subsequent studies demonstrated that prevalence rises substantially in more severe forms of impairment, with estimates suggesting that up to 80% of individuals with severe to profound ID experience significant feeding-related difficulties (Perske, 1977). More recent studies continue to support this trend, indicating that feeding problems remain a persistent and clinically significant concern in this population.

International evidence further highlights the extent and complexity of feeding difficulties in children with ID. In a descriptive study examining 144 children with ID, nearly all participants exhibited feeding difficulties, with approximately 79% showing disorders in feeding skills, 73.6% showed selectivity, and 63.9% showed food refusal. Problems related to aspiration risk were less frequent but still clinically noteworthy (Rezaei et al., 2011). In addition, children with Down syndrome (DS), one of the most common genetic causes of ID, demonstrate feeding difficulties in approximately 31% to 80% of cases during childhood, with

persistence into adulthood reported in 25–31% of individuals (Field et al., 2003; Hennequin et al., 2005; Pipes & Holm, 1980).

In the Indian context, evidence from children aged 3–10 years indicates that approximately 46.4% of children with ID experience feeding problems (Crasta et al., 2014). Another study done on 150 children with developmental disabilities found the highest mean behavioural feeding problem score in ID at (M=66.6), surpassing autism (M=58.6; Verma et al., 2025).

Feeding problems in children with ID are heterogeneous, affecting multiple functional domains of feeding behaviour and physiology. Linscheid (1983) identified ten distinct categories of feeding problems in individuals with ID, including tantrums during meals, bizarre food habits, multiple food dislikes, food texture selectivity, difficulties with chewing, sucking or swallowing, delayed self-feeding skills, pica, overeating, inadequate intake leading to malnutrition, and rumination.

Children with ID frequently present with delays and deficits in fundamental feeding skills, including chewing, self-feeding, and bolus manipulation. These impairments may manifest as inability or refusal to bring food to the mouth, poor coordination in chewing, and inefficient swallowing of food or liquids (Cooper et al., 1995; O'Brien et al., 1991). Such difficulties are often associated with delayed motor development, poor coordination and reduced learning capacity, all of which interfere with the acquisition of age-appropriate feeding abilities.

Children with ID often exhibit food refusal and selective eating behaviours. These can present as long mealtimes, expelling food, refusal to eat certain food groups or avoidance of certain textures or tastes. Selective eating patterns are often persistent and may continue into adulthood (Johnston, 1993; Parry-Jones, 1994; Riordan et al., 1984). In addition, there have

been reports of rumination and other atypical feeding behaviour. Such behaviours can severely restrict dietary variety and result in poor nutritional intake.

In children with moderate to severe ID, swallowing difficulties are of special concern because they increase the risk of aspiration and related respiratory complications. Rezaei et al. (2011) found that more than one-third of children with ID presented with risk factors for aspiration, underscoring the clinical importance of a comprehensive assessment of swallowing in this population.

Children with severe to profound ID are at increased risk for multiple co-occurring feeding difficulties including deficits in feeding skills, behavioural feeding problems and impairments of swallowing (Matson et al., 1991; Rezaei et al., 2011). These challenges are often interrelated and can have detrimental impacts on nutritional status, health outcomes and engagement in family mealtimes. Therefore, a comprehensive evaluation and individualised intervention strategies tailored to the child's cognitive and functional level are important.

Impact of Feeding Difficulties on the Child

Feeding problems can result in disrupted mealtimes, undernutrition, constipation, growth failure, aspiration risks, and frequent hospitalisations due to aspiration pneumonia (Andrew & Sullivan, 2010b; Dalpatadu et al., 2025; Sullivan et al., 2000). Factors such as gross motor skills, seating and positioning for feeding, oral motor dysfunction, effectiveness of swallowing, co-morbidities and feeding-related behaviours all influence a child's ability for safe and effective feeding (Andrew & Sullivan, 2010a). These issues restrict the practice and development of age-appropriate feeding skills in children since they are predominantly confined to the safe and recommended consistencies or textures (Borowitz & Borowitz, 2018), thus making their feeding skills inappropriate for their age (Goday et al., 2019). This affects the child's growth and development of age-appropriate feeding skills, thereby missing out on

the critical periods (Andrew & Sullivan, 2010a; Fischer & Silverman, 2007; Lefton-Greif & Arvedson, 2016). Children with feeding problems are more likely to have a probable developmental delay (Putnick et al., 2022).

Research into feeding problems among children with ASD has consistently demonstrated that feeding difficulties disrupt social interaction in mealtimes and decrease opportunities for shared attention, turn-taking and communication; therefore, it limits the social learning experience taking place in daily activities (Marshall et al., 2014; Rogers et al., 2012; Twachtman-Reilly et al., 2008).

Ten Hoopen et al. (2020) assessed the HRQoL in 88 children with ASD aged between 2 and 10 years, of whom 84% were male. Results indicated that the HRQoL was substantially reduced in children with ASD compared with population norms. Difficulties were most frequently reported in usual activities (76%) and self-care (60%), indicating significant functional limitations in daily life. Approximately 48% of the children were reported to experience anxiety or depressive symptoms, while pain or discomfort was reported among 27%, and mobility problems among 18%.

A cross-sectional pilot study by Grot et al. (2024) examined the feeding problems, eating disorders, and nutritional status among Polish children and adolescents with NDDs. The results showed that feeding problems, namely food selectivity, refusal and abnormal eating patterns, were very common in this group and often resulted in an increased risk of nutritional deficiencies or unbalanced diets. Almost all the participants showed signs of either malnutrition or overconsumption of some specific food items, which were attributed not to typical appetite regulation but rather to inflexible food preferences and heightened sensory reactivity. The consequences of feeding difficulties are not limited to the child. Because caregivers play a

central role in feeding management, they frequently experience significant emotional, physical, social, and financial challenges while addressing their child's feeding needs.

Impact of Feeding Difficulties on Caregiver

Feeding is often a two-way process in which the child's feeding difficulties significantly affect the caregivers, putting them under considerable physical and emotional strain. Emotional discomfort, compromised caregiver well-being, and strained child-caregiver interactions are all common outcomes of feeding problems (Arvedson et al., 2020; Greer et al., 2007). Caregivers of children with NDDs report feeling tired and unwell (Reis et al., 2020). Many caregivers also feel unprepared for the complicated demands of feeding or blame themselves for their child's problems (Rama et al., 2022), which can negatively affect their self-efficacy, confidence in parenting and self-esteem (Craig et al., 2003; Greer et al., 2007; Sherman et al., 2019).

Yap et al. (2025) reported that the caregivers of children facing feeding difficulties often claim inadequate access to feeding services, which leads to variable advice and increased reliance on trial-and-error approaches. Caregivers also often negotiate different family members' opinions about feeding strategies, including those of extended family members, which can undermine consistency and exacerbate the stress associated with feeding. Furthermore, the meals had to be continuously adapted due to the highly selective food preferences of their child, based on texture, presentation, or brand. Although these adaptations helped minimise mealtime distress, they contributed to emotional exhaustion and worried them due to the reinforcement of restrictive eating patterns. In fact, studies have shown that the severity of the feeding difficulties is associated with higher levels of parenting stress (Thullen & Bonsall, 2017).

Suresh et al. (2014) found that caregivers of children with ASD and ID experienced levels of overall burden similar to those of caregivers of children with ID alone. However, the financial burden and the burden due to the effects on the physical health of other family members were higher among the primary caregivers of the ID group. The burden due to the effects on family interaction was higher in the primary caregivers of the co-occurring ASD and ID group.

Winston et al. (2010) explored how feeding concerns impact the daily occupations and roles of mothers parenting children with feeding difficulties. Mothers indicated that mealtimes took up much of their time and energy, often dominating daily schedules and taking away from self-care, leisure and social participation. Qualitative findings further highlighted increased emotional distress, perceived blame regarding their child's nutritional experiences, and heightened vigilance during mealtimes. Caregivers frequently described stress, anxiety, feelings of failure, and self-doubt, which may negatively affect their QoL (Lowes et al., 2016).

Compared to caregivers of typically developing children and children with other developmental disorders, caregivers of children with ASD have been found to experience higher levels of parental stress (Estes et al., 2013; Hayes & Watson, 2013). Specifically, Gent et al. (2024) examined the impact of feeding difficulties on caregivers of autistic children using the FS-IS as an outcome measure, and reported significant caregiving burden across emotional, social, and practical domains. Persistent caregiver stress and burden may adversely affect multiple aspects of caregiver well-being. Consequently, recent research has increasingly focused on understanding the QoL of caregivers caring for children with neurodevelopmental disorders and feeding difficulties.

Quality of Life of Caregivers of Children with NDDs

Caregivers of children with feeding problems experience high levels of stress that

subsequently impact their QoL. Davy et al., (2022) highlighted the impact on caregivers' QoL, which influenced their own social participation levels for leisure, community access and employment.

In a cross-sectional study conducted by Ten Hoopen et al. (2020) to examine both health-related and care-related QoL in caregivers of children with ASD, revealed marked differences between primary and secondary caregivers. Primary caregivers, who were predominantly biological mothers, reported substantial health challenges despite having average overall health-related quality of life (HRQoL) scores that were not significantly lower than population norms. 40% of primary caregivers reported experiencing anxiety or depression symptoms, while 42% reported experiencing pain or physical discomfort. 21% of respondents said they had trouble carrying out their regular daily tasks, which illustrates the functional impact of caregiving duties. Secondary caregivers, who were mostly fathers, on the other hand, reported significantly fewer health issues, with only 15% reporting anxiety or sadness and relatively minor issues in other areas.

Another study conducted in Sri Lanka assessing the caregiver QoL included the primary caregivers (predominantly mothers) of children diagnosed with CP (Dalpatadu et al., 2025). The results demonstrated that caregiver QoL was significantly compromised, particularly in the psychological and social domains. Caregivers of children with more severe feeding difficulties (such as prolonged feeding times, choking, coughing during meals, poor weight gain, and complete reliance on feeding with caregiver support) reported lower overall QoL scores. Many caregivers reported that feeding was the most stressful daily caregiving activity, often dominating their routine and contributing to chronic fatigue. Caregiver QoL was impacted by the severity of CP, but not the child’s nutritional status.

In the Indian context, Samuel et al. (2023) explored the caregivers' experience in

feeding children with developmental disabilities. They found that feeding such children is often emotionally and physically taxing, confusing and stressful for the caregivers. Mothers, in particular, bear a disproportionate amount of the strain when it comes to handling the feeding difficulties and mealtime management. This continuous duty, influenced by societal norms and a lack of external support, affects their daily routines and emotional well-being, both of which lower caregivers' quality of life. Given the substantial impact of feeding and swallowing difficulties on caregivers, several assessment tools have been developed to evaluate caregiver burden and quality of life associated with dysphagia and feeding disorders. These tools help clinicians identify caregiver needs and guide family-centred intervention planning.

Tools to Assess the Dysphagia-Specific Caregiver Burden and QoL

One of the earliest instruments developed was the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ). Colodny (2008) developed the CMDQ, that intended to determine why caregivers might find it difficult to adhere to the Speech-Language Pathologists' (SLPs') dysphagia guidelines. It helps identify the emotional, social, and functional burdens that contribute to non-compliance. It is a 33-item questionnaire rated on a 5-point Likert scale (from strongly disagree to strongly agree) across three core domains: Quality of Life (QOL), Disagreement with the SLP (DSLP), and Avoidance (AV). These domains reflect whether caregivers reject advised techniques due to inconvenience, stress, or emotional distress, whether they dispute or disagree with clinical guidance, and whether they view dysphagia guidelines as burdensome. Non-compliant caregivers often exhibit higher CMDQ scores, particularly regarding disagreement with SLP guidelines and avoidance behaviours. While the CMDQ primarily focuses on factors influencing caregiver adherence to dysphagia management recommendations, subsequent tools were developed to directly assess the burden experienced by caregivers of individuals with swallowing disorders.

Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) (Shune et al., 2020) is a dysphagia-specific caregiver burden screening tool, developed to measure the burden related to dysphagia, particularly among caregivers of adults with swallowing difficulties. It is a 26-item questionnaire divided across two subscales: Part A consists of 10 items that assess the behavioural and functional changes that occurred in the caregivers' lives as a subsequent result of dysphagia-related caregiving. Part B consists of 16 items that measure the subjective caregiver stress as a result of the same. Part A is scored out of 10 points, and Part B is scored out of 16 points (1 point for every "yes" response and 0 points for every "no" response). The tool was validated on 26 caregivers of adults with dysphagia and demonstrated promising psychometric properties, including acceptable internal consistency, construct validity, and convergent validity with established measures such as the Eating Assessment Tool (EAT-10), the Zarit Burden Interview (ZBI), and the IDDSI Functional Diet Scale, with higher scores indicating a higher degree of swallowing-related caregiver burden. Caregivers can also indicate which of the listed statements is the most burdensome at the end of each subscale. The tool has also been adapted, translated and validated in Malayalam (Arakkal, 2023) and Kannada (Hegde et al., 2025). In addition to caregiver burden, researchers have also sought to evaluate the broader impact of dysphagia on caregivers' QoL, leading to the development of dedicated QoL measures.

Jain and Jagtap (2022) constructed the Quality of Life Due to Dysphagia Questionnaire for Caregivers of Individuals with Dysphagia (QOLC-M), which is a caregiver-administered QoL assessment tool developed to identify the impact of dysphagia on their ADL, feelings and attitudes and feeding-related problems. QOLC-M was originally constructed in Marathi and validated among 30 caregivers of adults with mechanical or neurological oropharyngeal dysphagia, including both oral and tube-fed patients. It was developed taking the ICF and CMDQ codes as references. The questionnaire consists of 42 items organised into three major

domains: Activities of Daily Living and Social Aspects (ADLS), Feelings and Attitudes (FA), and Feeding-related concerns, including sections specific to oral feeding and tube feeding. The ADLS domain comprises 14 statements that assess how caregiving of dysphagia affects daily routines, work, and social activities. It addresses problems with preparing food, supervision with eating, and reduced participation in social or leisure activities. The FA domain contains 12 statements about the emotional burden on the caregiver, including stress, anxiety, frustration and worry about the patient's dysphagia and the psychological toll of long-term caregiving. The feeding domain contains 16 items: six general items for caregivers who feed their care recipients, and five specific items for oral feeders and five for tube feeders. The frequency and severity of caregiver difficulties, such as stress in meal preparation, social restrictions, anxiety about aspiration, emotional exhaustion, changes in family routines, and concerns about feeding safety, are assessed using a 5-point Likert scale. These findings show factors responsible for the increase in the level of burden for caregivers, such as anxiety and depression in caregivers. It emphasises the significant impact of dysphagia on caregivers' emotional well-being, social participation and everyday functioning. The psychometric evaluation indicated excellent reliability and validity. The internal consistency was very high, and the test reliability was strong, which suggests that QOLC-M is a stable and reliable tool for clinical use. Although these instruments provide valuable information about caregivers of persons with dysphagia, they were developed mainly for adults. The requirement for a child-specific measure resulted in the development of instruments that focus on the caregivers of children with feeding and swallowing difficulties.

The Feeding/Swallowing Impact Survey (FS-IS, Lefton-Greif et al., 2014) has made it possible to better identify and address the needs and QoL of caregivers of children with feeding deficits. The FS-IS is a caregiver- reported tool designed to assess the HRQoL of caregivers of children with feeding difficulties. The 18-item questionnaire was developed for a better

understanding of the challenges experienced by caregivers of children with feeding difficulties in three key areas: daily activities, worry, and feeding difficulty. A 5-point Likert scale is used, where a score of "1" indicates "never" and "5" indicates "almost always," with higher scores signifying a poorer QoL for the caregiver. Principal Component Analysis (PCA) with promax rotation identified three factors corresponding to the subscales of daily activities, worry, and feeding difficulties. The reliability of the results surveyed in 164 children with feeding difficulties was demonstrated by the strong Cronbach alphas (total score = 0.89) that showed the internal consistency of these subscales. The PEDS-QL™ Family Impact Module (FIM) (Davis et al., 2010). It was used to validate the scale, and a significant correlation was found. The scale also effectively identifies differences in caregiver impact by successfully differentiating between caregivers of children with severe feeding/swallowing problems (such as those requiring feeding tubes) and those without such severe problems. Caregivers of children with more severe problems, like those using feeding tubes, have more interference in their daily tasks, which FS-IS could detect. This suggests that the tool is sensitive to differences in the severity of children's conditions and how they affect the caregivers.

This tool has been translated and validated in a number of languages since it was first created in English (Lefton-Greif et al., 2014). These include Turkish (Serel Arslan et al., 2018), South African (Bestenbier, 2021), Persian (Mokhlesin et al., 2024), Brazilian Portuguese (Rama et al., 2022), Italian (Baffi et al., 2025), and Kannada (Mathew, 2024).

Turkish version of FS-IS

The Turkish version of FS-IS (T-FS-IS, Serel Arslan et al., 2018) was clinically validated on 117 caregivers of children with CP (1-4 years). The Videofluoroscopic Swallowing Study was used to evaluate swallowing function, and the Penetration-Aspiration Scale (PAS) was used to determine the degree of penetration and aspiration. The internal consistency, test-retest reliability, construct validity, and discriminant validity of the T-FS-IS

were investigated. Internal consistency was excellent with Cronbach alphas all above 0.8 (Total score = 0.99, daily activities = 0.98, worries = 0.98, and feeding difficulties = 0.96). Excellent test-retest reliability was demonstrated by the intraclass correlation coefficient of 0.93. The T-FS-IS's three subscales—daily activities, worry, and feeding difficulties—as well as the total score, showed a strong correlation with the PAS scores. According to PAS, caregivers whose children had aspiration scored worse on the T-FS-IS total and its subscales than caregivers whose children did not have airway aspiration ($p<0.01$). The T-FS-IS is a valid and reliable tool for assessing how swallowing difficulties affect caregivers of children with CP.

South African version of FS-IS

The South African version of the FS-IS (Bestenbier, 2021) was clinically validated on 32 caregivers of children with feeding and swallowing difficulties. The children presented with a wide range of feeding difficulties, including non-oral feeding, modified oral diets, and selective eating behaviours. Psychometric evaluation demonstrated high internal consistency (Cronbach's alpha = 0.827) and excellent intra- and inter-rater reliability with 100% agreement, confirming the reliability of the adapted FS-IS. The study also underscored the significant burden experienced by caregivers. Getting help from others (50%) and leaving the child in another person's care due to fear related to feeding safety (62.5%) were the most difficult daily activities. Most caregivers reported major concerns regarding their child's general health (84%) and whether they were doing enough to manage the feeding difficulties (50%). Despite these concerns, fewer caregivers reported practical feeding preparation difficulties, with most indicating no major issues regarding meal preparation time or conflicting feeding advice from professionals and family members. The findings confirmed that the South African FS-IS is a reliable, valid, and culturally appropriate tool for identifying caregivers experiencing reduced quality of life due to caring for a child with feeding and swallowing difficulties.

Brazilian Portuguese version of FS-IS

The Brazilian Portuguese version of the FS-IS (Pt-Br-FS-IS, Rama et al., 2022) was clinically validated on 95 primary caregivers of children with feeding and swallowing disorders presenting with varying severities of dysphagia. Swallowing severity was classified using the Paediatric Dysphagia Evaluation Protocol (PDEP) and caregiver QoL was additionally compared with scores from the Paediatric Quality of Life Family Impact Module (PedsQL™ FIM) to establish construct validity. Psychometric analysis demonstrated good internal consistency (Cronbach's alpha = 0.83), excellent test–retest reliability, and confirmatory factor analysis supporting the original three-domain structure of the FS-IS. Caregivers of children with more severe dysphagia reported greater impairment in feeding-related QoL, confirming the clinical validity of the Brazilian Portuguese FS-IS as a reliable caregiver-centred dysphagia assessment tool.

Persian version of FS-IS

The Persian version of the FS-IS (P-FS-IS, Mokhlesin et al., 2024) was clinically validated on 97 Iranian mothers of children with CP and associated dysphagia aged 2–18 years. The study identified two major factors explaining 59.71% of the cumulative variance, reflecting caregiver burden related to feeding difficulties and emotional well-being. The Persian FS-IS demonstrated excellent psychometric properties, including high internal consistency (Cronbach's alpha = 0.95) and excellent test–retest reliability (Intraclass Correlation Coefficient = 0.97). Known-group validity analysis showed that caregivers of children with more severe swallowing impairments reported significantly poorer QoL scores, confirming the tool's clinical sensitivity for assessing caregiver burden associated with paediatric dysphagia.

Italian version of FS-IS

The Italian version of the FS-IS (FS-IS-IT; Baffi et al., 2025) was clinically validated on 207 Italian parents (107 mothers and 100 fathers) of children with feeding and swallowing difficulties. The study underwent a rigorous cross-cultural adaptation process that included forward and backward translation, expert review and pilot testing. Psychometric evaluation demonstrated excellent internal consistency, with Cronbach's alpha coefficients ranging from 0.88 to 0.96 across the three domains (daily activities, worry, and feeding difficulties) and the total score. Confirmatory factor analysis supported the original three-factor structure of the FS-IS, confirming the conceptual equivalence of the Italian version. The FS-IS-IT also demonstrated good construct validity, with significant associations between caregiver QoL scores and the severity of the child's feeding and swallowing difficulties. Importantly, the study validated the instrument for both members of parental dyads, showing that mothers generally reported a greater feeding-related impact than fathers, although both experienced substantial caregiver burden. The findings support the FS-IS-IT as a reliable, valid, and culturally appropriate instrument for assessing the impact of paediatric feeding and swallowing disorders on Italian caregivers and for identifying families requiring additional support.

Kannada version of FS-IS

The Indian (Kannada) version of FS-IS, FS-IS-K (Mathew, 2024), was clinically validated in 60 children diagnosed with CP aged 2-18 years (Mathew, 2024). The Feeding Handicap Index (FHI; Shabnam & Swapna, 2023) was used to gauge the degree of feeding difficulties, and "The Burden of Persons with Aphasia on the caregivers" (Swati, 2008) was used to assess the concurrent validity of the modified tool. Statistical analysis revealed an average total score of 2.54, which indicated a decrease in caregiver QoL. The family's inability to make plans or go out to eat, other people's reactions to the child's feeding issue, worries about whether the child will ever eat and drink like typical children, and conflicting views from

family members and professionals regarding feeding were the main concerns raised by caregivers. The trans-adapted tool was found to be statistically valid and reliable, with high test-retest reliability of 0.89 and good internal consistency of 0.99. The scale is thereby considered a potent tool to measure the impact of swallowing disorders on caregivers of children with CP.

To summarise, the review of literature highlights the high prevalence of feeding and swallowing difficulties in children with NDDs, particularly in ASD and ID, which have a considerable impact on caregiver quality of life. When a caregiver's quality of life is significantly compromised, it can affect both the caregiver and the child, often creating a cycle in which stress and feeding difficulties reinforce one another. Thus, assessment of caregiver QoL is essential as it helps speech-language pathologists understand the impact of pediatric feeding difficulties on the family**,** identify caregivers who need support, improve treatment planning and adherence, and ultimately promote better outcomes for both the child and the caregiver. In the Indian context, though the Kannada version of FS-IS has been developed with strong psychometric properties, its validation was limited to caregivers of children with CP. Keeping this in view, the present study was proposed. The method employed in the present study is described in the next chapter.

Chapter 3

Methods

This study aimed to validate the Feeding/Swallowing Impact Survey-Kannada (FS-IS-K; Mathew, 2024) among caregivers of children with feeding difficulties associated with neurodevelopmental disorders (NDDs), specifically Autism Spectrum Disorder (ASD) and Intellectual Disability (ID). The primary objective of the study was to establish the clinical validity and reliability of the FS-IS-K among caregivers of children with ASD and ID. In addition, the study sought to compare the feeding-specific caregiver health-related quality of life (HRQoL), measured using FS-IS-K, across the factors related to the child, including the severity of the disorder (ASD and ID), age group, and severity of feeding difficulties.

To further understand feeding-related challenges, the study compared the Feeding Handicap Index (FHI; Shabnam & Swapna, 2023) scores between the ASD and ID groups and across age groups. The relationships between caregiver HRQoL and feeding difficulties were also examined by assessing the correlations between total FHI scores and FS-IS-K scores, as well as between caregiver-reported severity of feeding difficulties and FS-IS-K scores.

Research Design

The study employed an analytical cross-sectional research design.

Ethical considerations

The study was conducted in accordance with the ethical standards for Bio-behavioural Research involving human subjects 2.0 (AIISH, 2023). The study was approved by the Ethical Committee of AIISH (SH/IRB/M.5/SLP.10/2025-26) (Appendix 1). The selection of participants and their involvement complied with all ethical requirements. The caregivers were informed about the study and its objectives prior to field testing, and their agreement to participate was acquired by signing a consent form (Appendix 2).

This study was conducted in two phases: Clinical validation of the tool and assessment of test-retest reliability.

Phase I: Clinical validation of FS-IS-K by administering it to the caregivers of children with ASD and ID.

The data collection was carried out on the primary caregivers of children with pediatric feeding disorder (PFD) secondary to ASD and ID.

Participants

To establish the clinical validity, primary caregivers of children with PFD secondary to ASD and ID in the age range of 2–12 years were included. Caregivers aged 18 years or older, who were able to read Kannada, were included. The participants were recruited from among those who had reported to the Department of Clinical Services and the Department of Special Education of the All India Institute of Speech and Hearing (AIISH), Mysuru and from a few special schools in Mysuru. The children who were recruited for the study were enrolled for speech therapy, occupational therapy and/or special education in the concerned facilities.

Caregivers with any significant health issues or psychiatric illnesses were excluded from the study. Furthermore, caregivers who had previously sought intervention for the feeding difficulties of their child were excluded to maintain uniformity. The modified Kuppuswamy socioeconomic scale (Mandal & Hossain, 2025) was used to determine the socioeconomic status (SES) of the caregivers.

The children included were diagnosed with ASD and ID by a qualified team of professionals, including a speech-language pathologist, paediatrician, and clinical psychologist. The diagnosis and severity of ASD were determined using the Indian Scale for Assessment of Autism (ISAA), a standardised Indian tool developed to assess autism severity across multiple behavioural domains (Chakraborty et al., 2015). The diagnosis and severity of

ID were determined according to the criteria outlined in the International Classification of Diseases, 11th Revision (ICD-11; World Health Organization, 2019).

A total of 60 caregivers (male = 2, female = 58) with a mean age of 35.07 ± 6.97 years participated in the study. Among the caregivers, 54 were mothers, 2 were fathers, and 4 were others (grandmothers, aunts). The care recipients were children with ASD and ID with a mean age of 5.82 ± 2.57 years. The mean age at identification of feeding difficulties was 2.38 ± 1.26 years. Of the 60 children, 34 belonged to the ID group, among whom 4 had co-occurring Down syndrome, and 7 had seizure disorder. Within the ASD group, 7 children had co-morbid ID. The demographic details of caregivers and care recipients are presented in Tables 3.1 and 3.2.

Table 3.1

Demographic details of the caregivers

Variable	**Category**	**N**
Gender	Male	2
	Female	58
Socioeconomic Class	Upper	5
	Upper Middle	26
	Lower Middle	23
	Upper Lower	6
	Lower	0
Family type	Joint	19
	Nuclear	41

Note. n = number of participants.

Table 3.2

Demographic details of the care recipients

Variable	**Category**	***n***
Gender	Male	46
	Female	14
Diagnostic Group	ASD	26
ASD Severity	Mild	20
	Moderate	6
	ID	34
ID Severity	Mild	27
	Moderate	7
Care Recipient Status	Completely Dependent	28
	Partially Dependent	29
	Independent	3

Note. n = number of participants. ID = Intellectual Disability; ASD = Autism Spectrum Disorder.

Procedure

Each caregiver was assessed individually and the required details were collected face-to-face in a relatively noise-free environment with minimum distractions. Prior to data collection, the purpose and procedures of the study were explained to the participants, following which a written informed consent was obtained from all caregivers who agreed to participate in the study. The participants were selected based on the criteria mentioned above. The demographic data of the participants, such as caregivers' and care recipients' age, gender, age of identification of feeding deficits, caregiver education, and care recipient dependency status, were collected and detailed in the demographic form. Information on the diagnosis and

severity of ASD and ID was obtained from the care recipients' clinical case files. Only those records in which the diagnosis and severity had been assessed or reviewed within the previous six months were considered, ensuring that the classification reflected the child's current level of functioning. The modified Kuppuswamy socioeconomic scale (Mandal & Hossain, 2025) was used to classify the caregivers into different levels of socioeconomic class.

Two questionnaires were administered. FS-IS-K (Appendix 3) was given to the caregivers for self-administration. The 18-item questionnaire was developed for a better understanding of the challenges experienced by caregivers of children with PFD in three key areas: daily activities, worry, and feeding difficulty. A 5-point Likert scale is used, where a score of "1" indicates "never" and "5" indicates "almost always," with higher scores signifying a poorer QoL for the caregiver.

To assess the relationship between the severity of feeding deficits and caregiver HRQoL, the FHI was also administered by the clinician. FHI is a valid and reliable 38-item instrument with three domains: Physical, Functional and Emotional. For the present study, only the Physical and Functional domains were assessed. These domains assess observable feeding and swallowing difficulties and their impact on the child's feeding performance, which are more closely related to the caregiver experiences measured by the FS-IS-K. In contrast, the Emotional domain focuses on the child's affective responses during mealtimes and was therefore not included in the present analyses. The responses on this clinician-administered tool were assessed on a 3-point Likert-type scale ranging from 0 to 2 (0: never has the problem, 1: sometimes has the problem, 2: always has the problem). Additionally, the caregivers were asked to rate the overall severity of the feeding difficulty based on a 7-point rating scale (1 = normal; 4 = moderate problem; 7 = severe problem) in the FHI.

At the end of the questionnaire administration, general guidelines related to the

management of the care recipient's feeding difficulties were provided to the caregivers, and they were counselled regarding the need to attend paediatric feeding therapy services for further intervention and support. The entire process, including assessment, counselling, and data collection, took approximately 30 minutes.

Phase II: Assessment of test-retest reliability

To establish test–retest reliability, 20% of the participants (n = 12) were randomly selected and reassessed using the FS-IS-K questionnaire, two weeks following the initial data collection, to examine the consistency of responses over time.

Statistical Analysis

The scores of the FS-IS-K, including the subscale scores, total score, and average total score, along with the total and domain-specific scores of the FHI, were computed and tabulated for each participant. Statistical analyses were carried out using Statistical Package for the Social Sciences (SPSS), version 26. Prior to analysis, the normality of the data was assessed using the Shapiro–Wilk test. Descriptive statistics were computed for FS-IS-K and FHI scores, and frequency and percentage distributions were obtained for individual FS-IS-K items. Test-retest reliability of the questionnaire was established using the Intraclass Correlation Coefficient (ICC), computed using a two-way mixed-effects model with absolute agreement. Comparative and correlational analyses were performed to examine differences in FS-IS-K and FHI scores across disorders, age groups, and severity levels, and to explore the relationship between feeding difficulties and feeding-specific caregiver quality of life. Appropriate statistical methods were selected based on the nature of the variables. The findings obtained from these analyses are presented in the next chapter.

Chapter 4

Results

This study aimed to validate the Kannada version of the Feeding/Swallowing-Impact Survey (FS-IS-K; Mathew, 2024) among caregivers of children with feeding difficulties associated with Autism Spectrum Disorder (ASD) and Intellectual Disability (ID). In addition to establishing the clinical validity and reliability of the tool, the study aimed to analyse the frequency and percentage distribution of responses to individual FS-IS-K items among caregivers of children with ASD and ID. Comparisons of FS-IS-K scores between caregivers of children with mild and moderate severity levels of the disorder and between caregivers of younger children (2–6 years) and older children (6–12 years) in each group were also planned. To better understand the relationship between the severity of feeding difficulties and caregiver health-related quality of life (HRQoL), the study also investigated the correlation between Feeding Handicap Index (FHI; Shabnam & Swapna, 2023) scores and FS-IS-K scores. Through these analyses, the study sought to explore how the severity of the child's condition, age, disorder, and extent of feeding difficulties influence feeding-specific caregiver quality of life.

The FS-IS-K consists of 18 items grouped under three subscales, i.e., daily activities, worry, and feeding difficulties. These subsections include 5, 7, and 6 items, respectively. A 5-point rating scale was used, where "never" indicated no impact (score: 1), "almost never" indicated minimal impact (score: 2), "half the time" indicated moderate impact (score: 3), "very often" indicated frequent impact (score: 4), and "almost always" indicated severe impact on the caregiver's HRQoL (score: 5). The total scores ranged from 18-90 and the possible range of scores in each subscale include 5-25, 7-35 and 6-30 respectively. This questionnaire was self-rated by the caregivers.

The clinical validity was established by administering the tool on 60 participants, who were the primary caregivers of children aged 2–12 years diagnosed with Pediatric Feeding Disorder secondary to either ASD or ID. Of the total participants, 26 were caregivers of children with ASD and 34 were caregivers of children with ID. Among the children with ID, 24 were male, and 10 were female, whereas the ASD group included 22 male and 4 female children. Within the ASD group, 20 children were classified as mild and 6 as moderate based on the severity of the disorder. Within the ID group, 27 children were classified as having mild severity and 7 as having moderate severity. In addition, the FHI was used to assess the severity of feeding difficulty.

Test–retest reliability was assessed in 20% of the participants ($n = 12$) after an interval of two weeks from the initial data collection. Reliability analysis was performed using the Intraclass Correlation Coefficient (ICC). An ICC value of ≥ .90 was considered indicative of excellent reliability (Koo & Li, 2016). The total, subscale, and average total scores of the FS-IS-K, along with the scores obtained on the FHI, were tabulated and entered into IBM SPSS Statistics (Version 26) for statistical analysis. Descriptive statistics were computed for the total scores and subscale scores of the FS-IS-K and FHI. Frequency and percentage distributions were calculated for individual FS-IS-K items to examine response patterns among caregivers.

To compare FS-IS-K scores across severity levels within the groups, participants were classified according to the severity of the disorder (ASD and ID) into mild and moderate categories. Due to the small sample sizes within severity subgroups, normality testing was not performed for these comparisons. Therefore, a non-parametric approach was adopted, and comparisons between mild and moderate severity levels within the ASD and ID groups were performed using the Mann–Whitney U test.

The Shapiro–Wilk test was used to assess the normality of distribution for variables included in subsequent analyses. As the data were normally distributed, parametric statistical tests were employed. Two-way multivariate analysis of variance (MANOVA) was conducted to examine the effects of disorder (ASD and ID) and age group (2–6 years and 6–12 years) on FS-IS-K subscale scores and FHI domain scores. Subsequently, two-way analysis of variance (ANOVA) was performed to examine the effects of disorder and age group on FS-IS-K total scores and FHI total scores.

Pearson's correlation coefficient was used to examine the relationship between FHI scores and FS-IS-K scores. Spearman's rho correlation coefficient was used to determine the relationship between caregiver-reported severity of feeding difficulties and FS-IS-K scores. A *p*-value of less than .05 was considered statistically significant.

Although additional caregiver and care recipient characteristics, including caregiver gender, caregiver education, family type, socioeconomic status, care recipient gender, dependency status, and age at identification of feeding difficulties, were collected as part of the demographic profile, these variables were not subjected to statistical analysis in the present study, as the sample size was not sufficient to yield reliable comparisons across the subgroups formed by these variables.

The results of the study are presented in the following sections.

1. Test–retest reliability of the FS-IS-K
2. Frequency and percentage distribution of responses on individual FS-IS-K items
3. Comparison of FS-IS-K scores across severity levels of the disorder
4. Comparison of FS-IS-K scores across the disorder and age groups
5. Comparison of FHI scores across the disorder and age groups
6. Correlation between total FHI scores and FS-IS-K scores

7. Correlation between caregiver-reported severity of feeding difficulties and FS-IS-K scores

Test–Retest Reliability of the FS-IS-K

To assess the test–retest reliability of the FS-IS-K, the tool was re-administered to 20% of the total participants (n = 12), two weeks following the initial administration. Scores obtained during the first administration and the follow-up assessment were calculated, tabulated, and analysed using IBM SPSS software (Version 26). A two-way mixed-effects model with absolute agreement was used to compute ICC values. ICC values demonstrated excellent reliability for the total FS-IS-K score (ICC = .995) and for all subscales: Daily Activities (ICC = .987), Worry (ICC = .985), and Feeding Difficulties (ICC = .984). All ICC values exceeded the threshold of .90, indicative of excellent reliability (Koo & Li, 2016). Overall, the findings demonstrated high test–retest reliability of the FS-IS-K, supporting the consistency of the measure over time.

Frequency and Percentage Distribution of Responses on Individual FS-IS-K Items

Descriptive statistics were computed for the total and subscale scores of the FS-IS-K. The mean total FS-IS-K score was 53.93 (*SD* = 16.96), representing approximately 59.92% of the maximum possible score of 90. For Subscale 1, which assessed the impact of caregiving on activities of daily living, the mean score was 16.62 (*SD* = 5.65), corresponding to 66.48% of the maximum possible score of 25. Subscale 2, which evaluated caregiver-related worry, had a mean score of 21.22 (*SD* = 7.06), representing 60.63% of the maximum possible score of 35. Subscale 3, which assessed feeding-related difficulties, showed a mean score of 16.10 (*SD* = 6.28), corresponding to 53.67% of the maximum possible score of 30.

The average total score of the FS-IS-K was 3.00. This score was obtained by summing the responses across all 18 items and dividing the total by 18. The average total score reflects

the overall impact of feeding-related difficulties on the caregiver's HRQoL. The obtained mean and average scores suggested that feeding-related difficulties affected caregiver HRQoL, particularly in relation to caregiver worry, feeding-related stress, and daily caregiving demands. The percentage distribution of caregiver responses for each item in the FS-IS-K was also calculated. The results have been described below under each subscale.

Subscale 1 — Daily Activities

Within Subscale 1, Item 4 had the highest overall endorsement, which enquired about the impact of feeding difficulties on family outings and eating out. In all, 38 (63.3%) caregivers reported this difficulty "Very Often" or "Almost Always." In contrast, the lowest overall endorsement was found for Item 1, which reflected difficulties in carrying out daily routine activities, where 29 (48.3%) caregivers chose the higher frequency response categories, indicating a comparatively lower impact of this aspect of feeding difficulties.

Among caregivers of children with ASD, Items 3, 4, and 5 were most endorsed.13 (50.0%) caregivers endorsed these difficulties "Very Often" or "Almost Always." These items reflected reluctance to leave the child with others due to fear of feeding issues, the impact of feeding issues on family outings and having food outside, and caregiver fatigue related to managing feeding responsibilities. The modal response for Item 1 was "Never" (30.8%), and it received the lowest endorsement, suggesting that this aspect of feeding difficulties was less frequently reported in the ASD group.

Among caregivers of children with ID, the highest endorsement was observed for Item 4, with 73.5% reporting that feeding difficulties affected family outings and eating outside the home "Very Often" or "Almost Always." High endorsement was also observed for Item 3 (61.8%) and Item 5 (61.7%), reflecting challenges related to leaving the child with others and caregiver fatigue. The lowest endorsement was observed for Item 2, which reflected difficulty

in seeking help from others due to fear or reluctance of those individuals to feed or look after the child, with 50.0% selecting the higher-frequency categories. A notable finding was the marked difference between groups on Item 1 (difficulties in carrying out daily routine activities), where caregivers of children with ID most frequently selected "Very Often" (38.2%), whereas caregivers of children with ASD most frequently selected "Never" (30.8%), suggesting a greater perceived impact among the ID group for this aspect of feeding difficulties. Table 4.1 presents the frequency (*n*) and percentage (%) of caregiver responses for subscale 1 of the FS-IS-K.

Table 4.1

Frequency and Percentage Distribution of Caregiver Responses Across FS-IS-K Items: Subscale 1(Daily Activities)

Items	Rating scale	ASD *n*(%)	ID *n*(%)	Total *N*(%)
Item 1	1-Never	8 (30.8%)	5 (14.7%)	13 (21.7%)
	2-Almost Never	4 (15.4%)	3 (8.8%)	7 (11.7%)
	3-Half the time	5 (19.2%)	6 (17.6%)	11 (18.3%)
	4-Very Often	2 (7.7%)	13 (38.2%)	15 (25.0%)
	5-Almost Always	7 (26.9%)	7 (20.6%)	14 (23.3%)
Item 2	1-Never	7 (26.9%)	5 (14.7%)	12 (20.0%)
	2-Almost Never	1 (3.8%)	5 (14.7%)	6 (10.0%)
	3-Half the time	5 (19.2%)	7 (20.6%)	12 (20.0%)
	4-Very Often	9 (34.6%)	9 (26.5%)	18 (30.0%)
	5-Almost Always	4 (15.4%)	8 (23.5%)	12 (20.0%)
Item 3	1-Never	5 (19.2%)	7 (20.6%)	12 (20.0%)
	2-Almost Never	3 (11.5%)	3 (8.8%)	6 (10.0%)
	3-Half the time	5 (19.2%)	3 (8.8%)	8 (13.3%)
	4-Very Often	4 (15.4%)	9 (26.5%)	13 (21.7%)
	5-Almost Always	9 (34.6%)	12 (35.3%)	21 (35.0%)
Item 4	1-Never	5 (19.2%)	3 (8.8%)	8 (13.3%)
	2-Almost Never	4 (15.4%)	3 (8.8%)	7 (11.7%)
	3-Half the time	4 (15.4%)	3 (8.8%)	7 (11.7%)
	4-Very Often	6 (23.1%)	12 (35.3%)	18 (30.0%)
	5-Almost Always	7 (26.9%)	13 (38.2%)	20 (33.3%)
Item 5	1-Never	7 (26.9%)	8 (23.5%)	15 (25.0%)
	2-Almost Never	4 (15.4%)	2 (5.9%)	6 (10.0%)
	3-Half the time	2 (7.7%)	3 (8.8%)	5 (8.3%)
	4-Very Often	4 (15.4%)	13 (38.2%)	17 (28.3%)
	5-Almost Always	9 (34.6%)	8 (23.5%)	17 (28.3%)

Note. ASD = Autism Spectrum Disorder; ID = Intellectual Disability; FS-IS-K = Feeding/Swallowing Impact Survey-Kannada; n = frequency. Percentages are based on group totals (ASD n = 26; ID n = 34; Total N = 60).

Subscale 2 — Worry

Within Subscale 2, the highest overall endorsement was observed for Item 6, which reflected concerns regarding the child's health. Overall, 45 caregivers (75.0%) reported this concern "Very Often" or "Almost Always," indicating that health-related concerns were the

most prominent within the subscale. Item 7, reflecting concerns regarding the adequacy of the child's food intake, also demonstrated substantial endorsement, with 36 caregivers (60.0%) reporting higher-frequency concerns. In contrast, Item 9, reflecting concerns about choking or breathing problems during feeding, was the least endorsed overall. Twelve caregivers (20.0%) endorsed this concern "Very Often" or "Almost Always", while 39 caregivers (65.0%) endorsed "Never" or "Almost Never". Item 12, which captures concerns about impact on family members, was also relatively low in endorsement, with only 18 caregivers (30.0%) endorsing the higher frequency categories and 26 caregivers (43.3%) endorsing "Never."

Among caregivers of children with ASD, the most frequently endorsed item was Item 6, with 17 caregivers (65.4%) endorsing concerns about the child's overall health "Very Often" or "Almost Always." Conversely, Item 9 (worry about choking or breathing problems while eating) was endorsed by the fewest number of caregivers, with just 2 (7.7%) endorsing the higher frequency response categories and 19 (73.1%) responding "Never".

Among caregivers of children with ID, the most endorsed item was Item 6, concerning the child's overall health, with 28 caregivers (82.4%) reporting "Very Often" or "Almost Always." As previously, Item 9 was the least endorsed; however, there were more concerns than in the ASD group, with 10 caregivers (29.4%) endorsing "Very Often" or "Almost Always" and 17 caregivers (50.0%) endorsing "Never."

Although Item 9 had the lowest overall endorsement across both groups, choking or breathing difficulties were reported more frequently by caregivers of children with ID, with 14.7% endorsing "Almost Always," whereas no caregivers in the ASD group selected this response category. Table 4.2 presents the frequency (*n*) and percentage (%) of caregiver responses for subscale 2 of the FS-IS-K.

Table 4.2

Frequency and Percentage Distribution of Caregiver Responses Across FS-IS-K Items: Subscale 2 (Worries)

Items	Rating scale	ASD *n*(%)	ID *n*(%)	Total *N*(%)
Item 6	1-Never	5 (19.2%)	2 (5.9%)	7 (11.7%)
	2-Almost Never	2 (7.7%)	1 (2.9%)	3 (5.0%)
	3-Half the time	2 (7.7%)	3 (8.8%)	5 (8.3%)
	4-Very Often	6 (23.1%)	9 (26.5%)	15 (25.0%)
	5-Almost Always	11 (42.3%)	19 (55.9%)	30 (50.0%)
Item 7	1-Never	7 (26.9%)	9 (26.5%)	16 (26.7%)
	2-Almost Never	1 (3.8%)	3 (8.8%)	4 (6.7%)
	3-Half the time	3 (11.5%)	1 (2.9%)	4 (6.7%)
	4-Very Often	5 (19.2%)	8 (23.5%)	13 (21.7%)
	5-Almost Always	10 (38.5%)	13 (38.2%)	23 (38.3%)
Item 8	1-Never	10 (38.5%)	7 (20.6%)	17 (28.3%)
	2-Almost Never	1 (3.8%)	4 (11.8%)	5 (8.3%)
	3-Half the time	3 (11.5%)	5 (14.7%)	8 (13.3%)
	4-Very Often	9 (34.6%)	8 (23.5%)	17 (28.3%)
	5-Almost Always	3 (11.5%)	10 (29.4%)	13 (21.7%)
Item 9	1-Never	19 (73.1%)	17 (50.0%)	36 (60.0%)
	2-Almost Never	2 (7.7%)	1 (2.9%)	3 (5.0%)
	3-Half the time	3 (11.5%)	6 (17.6%)	9 (15.0%)
	4-Very Often	2 (7.7%)	5 (14.7%)	7 (11.7%)
	5-Almost Always	0 (0.0%)	5 (14.7%)	5 (8.3%)
Item 10	1-Never	5 (19.2%)	6 (17.6%)	11 (18.3%)
	2-Almost Never	6 (23.1%)	3 (8.8%)	9 (15.0%)
	3-Half the time	2 (7.7%)	4 (11.8%)	6 (10.0%)
	4-Very Often	4 (15.4%)	11 (32.4%)	15 (25.0%)
	5-Almost Always	9 (34.6%)	10 (29.4%)	19 (31.7%)
Item 11	1-Never	9 (34.6%)	6 (17.6%)	15 (25.0%)
	2-Almost Never	4 (15.4%)	6 (17.6%)	10 (16.7%)
	3-Half the time	4 (15.4%)	5 (14.7%)	9 (15.0%)
	4-Very Often	4 (15.4%)	10 (29.4%)	14 (23.3%)
	5-Almost Always	5 (19.2%)	7 (20.6%)	12 (20.0%)
Item 12	1-Never	12 (46.2%)	14 (41.2%)	26 (43.3%)
	2-Almost Never	5 (19.2%)	3 (8.8%)	8 (13.3%)
	3-Half the time	2 (7.7%)	6 (17.6%)	8 (13.3%)
	4-Very Often	4 (15.4%)	6 (17.6%)	10 (16.7%)
	5-Almost Always	3 (11.5%)	5 (14.7%)	8 (13.3%)

Note. ASD = Autism Spectrum Disorder; ID = Intellectual Disability; FS-IS-K = Feeding/Swallowing Impact Survey-Kannada; n = frequency. Percentages are based on group totals (ASD n = 26; ID n = 34; Total N = 60)33.

Subscale 3 — Feeding Difficulties

Within Subscale 3, item 16 was the most endorsed item, with the caregivers being unsure about the duration and persistence of the child's feeding and swallowing problems. Overall, 30 caregivers (50.0%) indicated this concern "Very Often" or "Almost Always." There was also a strong endorsement of Item 17, which represents differing views regarding feeding management from family and professionals. 28 caregivers (46.7%) selected the higher-frequency response categories for this item. In contrast, Item 15, reflecting the difficulty caregivers experience when others provide food items that are not suitable for their child, was endorsed low (60.0% of caregivers selected "Never" or "Almost Never"). Item 14, which indicated difficulty in preparing food that meets the child's specific feeding requirements , also had the lowest endorsement in the subscale, with half of the caregivers (50.0%) reporting "Never."

Among caregivers of children with ASD, Item 16 showed the highest endorsement, with 13 caregivers (50.0%) reporting uncertainty regarding the persistence of feeding difficulties "Very Often" or "Almost Always." In contrast, the lowest endorsement was observed for Items 14 and 15, with only 4 caregivers (15.3%) selecting the higher-frequency categories for each item. Item 14 reflected difficulties obtaining appropriate support or services for feeding concerns, while Item 15 reflected concerns regarding the caregivers' experience when others provide food items that are not suitable for their child. Notably, over half of ASD caregivers selected "Never" for both items (53.8%).

Among caregivers of children with ID, Items 16 and 17 demonstrated the highest endorsement, with 17 caregivers (50.0%) selecting "Very Often" or "Almost Always" for both items. These findings suggest that uncertainty regarding feeding progression and differing opinions regarding feeding management were key concerns among ID caregivers. The lowest endorsement was observed for Item 15, where 12 caregivers (35.3%) selected the higher-

frequency response categories. However, endorsement remained higher than that observed in the ASD group.

A notable group difference was observed for Item 15. While 76.9% of caregivers of children with ASD selected "Never" or "Almost Never," the corresponding proportion among caregivers of children with ID was 47.0%, suggesting greater concern regarding others providing food items that are not suitable for their child in the ID group. Table 4.3 presents the frequency (*n*) and percentage (%) of caregiver responses for subscale 3 of the FS-IS-K.

Table 4.3

Frequency and Percentage Distribution of Caregiver Responses Across FS-IS-K Items: Subscale 3 (Feeding difficulties)

Items	Rating scale	ASD *n*(%)	ID *n*(%)	Total *N*(%)
Item 13	1-Never	12 (46.2%)	11 (32.4%)	23 (38.3%)
	2-Almost Never	4 (15.4%)	2 (5.9%)	6 (10.0%)
	3-Half the time	5 (19.2%)	7 (20.6%)	12 (20.0%)
	4-Very Often	2 (7.7%)	12 (35.3%)	14 (23.3%)
	5-Almost Always	3 (11.5%)	2 (5.9%)	5 (8.3%)
Item 14	1-Never	14 (53.8%)	16 (47.1%)	30 (50.0%)
	2-Almost Never	5 (19.2%)	2 (5.9%)	7 (11.7%)
	3-Half the time	3 (11.5%)	2 (5.9%)	5 (8.3%)
	4-Very Often	3 (11.5%)	8 (23.5%)	11 (18.3%)
	5-Almost Always	1 (3.8%)	6 (17.6%)	7 (11.7%)
Item 15	1-Never	14 (53.8%)	13 (38.2%)	27 (45.0%)
	2-Almost Never	6 (23.1%)	3 (8.8%)	9 (15.0%)
	3-Half the time	2 (7.7%)	6 (17.6%)	8 (13.3%)
	4-Very Often	2 (7.7%)	8 (23.5%)	10 (16.7%)
	5-Almost Always	2 (7.7%)	4 (11.8%)	6 (10.0%)
Item 16	1-Never	6 (23.1%)	8 (23.5%)	14 (23.3%)
	2-Almost Never	6 (23.1%)	3 (8.8%)	9 (15.0%)
	3-Half the time	1 (3.8%)	6 (17.6%)	7 (11.7%)
	4-Very Often	3 (11.5%)	8 (23.5%)	11 (18.3%)
	5-Almost Always	10 (38.5%)	9 (26.5%)	19 (31.7%)
Item 17	1-Never	7 (26.9%)	9 (26.5%)	16 (26.7%)
	2-Almost Never	3 (11.5%)	4 (11.8%)	7 (11.7%)
	3-Half the time	5 (19.2%)	4 (11.8%)	9 (15.0%)
	4-Very Often	6 (23.1%)	12 (35.3%)	18 (30.0%)
	5-Almost Always	5 (19.2%)	5 (14.7%)	10 (16.7%)
Item 18	1-Never	7 (26.9%)	11 (32.4%)	18 (30.0%)
	2-Almost Never	5 (19.2%)	3 (8.8%)	8 (13.3%)
	3-Half the time	8 (30.8%)	6 (17.6%)	14 (23.3%)
	4-Very Often	3 (11.5%)	7 (20.6%)	10 (16.7%)
	5-Almost Always	3 (11.5%)	7 (20.6%)	10 (16.7%)

Note. ASD = Autism Spectrum Disorder; ID = Intellectual Disability; FS-IS-K = Feeding/Swallow Impact Survey – Kannada; n = frequency. Percentages are based on group totals (ASD n = 26; ID n = 34; Total N = 60).

Comparison of FS-IS-K Scores Across Severity Levels of the Disorder

Prior to examining the effects of disorder and age group on FS-IS-K outcomes, comparisons were performed across severity levels of the disorder (mild versus moderate

ASD/ID) to determine whether severity contributed significantly to FS-IS-K scores. The null hypothesis H_{01} proposed that there would be no significant difference in FS-IS-K scores between caregivers of children with mild and moderate severity of ASD and ID. Given the small subgroup sample sizes, formal normality testing was not performed for these analyses. Therefore, non-parametric analyses using the Mann–Whitney U test were conducted. Median and interquartile range (*IQR*) values for FS-IS-K total and subscale scores are presented in Table 4.4.

Table 4.4

Median (IQR) values of FS-IS-K scores according to severity level within ASD and ID groups

FS-IS-K	ASD		ID	
	Mild Median (*IQR*)	Moderate Median (*IQR*)	Mild Median (*IQR*)	Moderate Median (*IQR*)
Subscale 1	17.00 (14.50)	15.00 (7.50)	18.00 (6.00)	18.00 (8.00)
Subscale 2	19.50 (14.50)	20.00 (12.25)	22.00 (11.00)	21.00 (7.00)
Subscale 3	12.00 (12.25)	15.50 (13.00)	16.00 (13.00)	21.00 (9.00)
Total	50.00 (40.50)	51.00 (25.00)	61.00 (26.00)	62.00 (18.00)

Note. IQR = Interquartile Range. Subscale 1 = Daily Activities; Subscale 2 = Worry; Subscale 3 = Feeding Difficulties. ASD = Autism Spectrum Disorder; ID = Intellectual Disability.

Mann–Whitney U analyses indicated no statistically significant differences between mild and moderate severity groups within either the ASD or ID groups for the FS-IS-K total scores or subscale scores (all $p > .05$). The results of the Mann-Whitney U test are presented in Table 4.5.

Table 4.5

Results of Mann–Whitney U test comparing FS-IS-K scores across mild and moderate severity levels within ASD and ID groups

FS-IS-K	ASD		ID	
	$\|Z\|$	p	$\|Z\|$	P
Subscale 1	0.09	.927	0.39	.700
Subscale 2	0.34	.737	0.04	.966
Subscale 3	1.47	.143	1.86	.063
Total	0.70	.484	0.79	.430

Note. $|Z|$ = absolute value of the Mann–Whitney U test statistic. Subscale 1 = Daily Activities; Subscale 2 = Worry; Subscale 3 = Feeding Difficulties. ASD = Autism Spectrum Disorder; ID = Intellectual Disability.

Within the ASD group, severity level did not significantly influence the FS-IS-K Subscale 1 (Daily Activities) scores ($|Z| = 0.09$, $p = .927$), Subscale 2 (Worry) scores ($|Z| = 0.34$, $p = .737$), Subscale 3 (Feeding Difficulties) scores ($|Z| = 1.47$, $p = .143$), or total FS-IS-K scores ($|Z| = 0.70$, $p = .484$). Similarly, within the ID group, no statistically significant differences were observed between mild and moderate severity levels for Subscale 1 (Daily Activities) scores ($|Z| = 0.39$, $p = .700$), Subscale 2 (Worry) scores ($|Z| = 0.04$, $p = .966$), Subscale 3 (Feeding Difficulties) scores ($|Z| = 1.86$, $p = .063$), or total FS-IS-K scores ($|Z| = 0.79$, $p = .430$).

These findings suggest that feeding-specific caregiver HRQoL measured using the FS-IS-K remained comparable across mild and moderate severity levels of ASD and ID. As no

statistically significant differences were observed across severity levels, and given the small subgroup sample sizes, the severity of disorder was not included as an independent variable in subsequent analyses. The null hypothesis H_{01} was therefore accepted.

Comparison of FS-IS-K Scores across the Disorder and Age Groups

Following the severity analyses, subsequent analyses examined whether FS-IS-K scores varied according to disorder (ASD and ID) and age group (2–6 years and 6–12 years). The null hypothesis H_{02} proposed that there would be no significant difference in FS-IS-K scores between caregivers of children with ASD and caregivers of children with ID, or between caregivers of younger children (2–6 years) and caregivers of older children (6–12 years). As the data were normally distributed, a two-way MANOVA was conducted to examine FS-IS-K subscale scores, and a two-way ANOVA was conducted for FS-IS-K total scores. Descriptive statistics for FS-IS-K scores according to age group and disorder categories are presented in Table 4.6.

Table 4.6

Descriptive statistics for FS-IS-K scores according to age group and disorder

FS-IS-K	ASD		ID	
	Younger *M (SD)*	Older *M (SD)*	Younger *M (SD)*	Older *M (SD)*
Subscale 1	16.38 (6.17)	14.92 (6.86)	17.58 (4.61)	17.07 (5.50)
Subscale 2	20.08 (8.21)	18.92 (7.64)	23.21 (6.00)	21.67 (6.65)
Subscale 3	15.92 (7.23)	13.77 (6.04)	17.42 (5.57)	16.60 (6.51)
Total	52.38 (20.01)	47.62 (18.46)	58.21 (13.88)	55.33 (16.22)

Note. Subscale 1 = Daily Activities; Subscale 2 = Worry; Subscale 3 = Feeding Difficulties. ASD = Autism Spectrum Disorder; ID = Intellectual Disability.

Descriptive statistics revealed that the caregivers of younger children showed slightly higher FS-IS-K total and subscale scores than the caregivers of older children within both disorder groups. A two-way MANOVA was conducted to evaluate the effects of disorder and age group on FS-IS-K subscale scores. No statistically significant multivariate main effect of disorder was observed [Wilks' $\Lambda = .95$, $F(3,54) = 0.87$, $p = .464$, partial $\eta^2 = .05$]. Similarly, age group did not show a significant multivariate effect on FS-IS-K subscale scores [Wilks' $\Lambda = .99$, $F(3,54) = 0.27$, $p = .845$, partial $\eta^2 = .02$]. The interaction between disorder and age group was also non-significant [Wilks' $\Lambda = .99$, $F(3,54) = 0.20$, $p = .899$, partial $\eta^2 = .01$]. These findings indicate that FS-IS-K subscale scores did not significantly differ according to age group, disorder, or their interaction. The partial η^2 values indicated negligible effect sizes for all multivariate effects. The *MANOVA* findings are presented in Table 4.7.

Table 4.7

Results of two-way MANOVA analyses examining effects of age group and disorder on FS-IS-K subscale scores

	Wilks' Λ	F	P	Partial η^2
Disorder	.95	0.87	.464	.05
Age group	.99	0.27	.845	.02
Disorder × Age	.99	0.20	.899	.01

Note. df = 3 for all effects; error df = 54. Wilks' Lambda (Λ) is reported as the multivariate test statistic. Partial η^2 = partial eta squared.

Follow-up univariate analyses further demonstrated no statistically significant effects for individual FS-IS-K domains (all $p > .05$). No statistically significant main or interaction

effects were observed for Subscale 1, Subscale 2, or Subscale 3 scores (all $p > .05$). The findings of the univariate analysis are presented in Table 4.8.

Table 4.8

Results of univariate analyses (F and p values) for FS-IS-K subscale scores

	Subscale 1 *F(p)*	Subscale 2 *F(p)*	Subscale 3 *F(p)*
Disorder	1.25 (.268)	2.55 (.116)	1.73 (.193)
Age group	0.44 (.511)	0.54 (.467)	0.82 (.370)
Age × Disorder	0.10 (.752)	0.01 (.916)	0.16 (.687)

Note. df = 1 for all effects; error df = 56. Subscale 1 = Daily Activities; Subscale 2 = Worry; Subscale 3 = Feeding Difficulties.

A two-way ANOVA was conducted to examine the effects of age group and disorder on FS-IS-K total scores. No statistically significant main effect of age group was observed [$F(1,56) = 0.75$, $p = .391$, partial $\eta^2 = .01$]. Similarly, the disorder type did not significantly affect FS-IS-K total scores [$F(1,56) = 2.34$, $p = .131$, partial $\eta^2 = .04$]. The interaction between age group and disorder was also not statistically significant [$F(1,56) = .05$, $p = .831$, partial $\eta^2 = .00$]. The partial η^2 values indicated negligible effect sizes for all effects, suggesting that neither disorder nor age group accounted for meaningful variance in FS-IS-K total scores. The ANOVA findings are presented in Table 4.9.

Table 4.9

Results of two-way ANOVA examining effects of age group and disorder on FS-IS-K total scores

	F	*p*	Partial η^2
Disorder	2.34	.131	.04
Age group	0.75	.391	.01
Disorder × Age group	0.05	.831	.00

Note. df = 1 for all effects; error df = 56. η^2 = partial eta squared.

These findings collectively indicate that FS-IS-K total and subscale scores did not differ significantly across disorder or age groups, and no significant interaction between disorder and age group was observed. The null hypotheses H_{02} were therefore accepted.

Comparison of FHI Scores Across the Disorder and Age Groups

Although FS-IS-K scores were comparable across disorder and age groups, further analyses examined whether the nature and severity of feeding difficulties, as measured by the FHI, differed between groups. Subsequent analyses examined whether FHI scores differed according to disorder type (ASD and ID) and age group (2–6 years and 6–12 years). The null hypothesis H_{03} proposed that there would be no significant difference in FHI scores (Physical domain, Functional domain, and total scores) between children with ASD and ID and between younger (2–6 years) and older children (6–12 years). Since the data were normally distributed, a two-way MANOVA was conducted to examine FHI domain scores (Physical and Functional), and a two-way ANOVA was conducted for FHI total scores. Descriptive statistics for FHI scores according to age group and disorder type are presented in Table 4.10.

Table 4.10

Descriptive statistics for FHI scores according to age group and disorder type

FHI	ASD		ID	
	Younger	Older	Younger	Older
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*
Domain 1	16.77 (6.17)	13.69 (4.89)	19.53 (6.54)	20.67 (4.72)
Domain 2	6.77 (2.80)	4.69 (2.10)	7.16 (4.39)	7.20 (3.41)
Total	23.54 (8.01)	18.38 (6.09)	26.68 (10.54)	27.87 (6.44)

Note. Domain 1 = Physical; Domain 2 = Functional. ASD = Autism Spectrum Disorder; ID = Intellectual Disability.

Descriptive statistics revealed that children with ID showed higher FHI scores than children with ASD. Within the ASD group, younger children demonstrated higher FHI scores than older children, whereas within the ID group, scores remained broadly comparable across age groups.

A two-way MANOVA was conducted to examine the effects of disorder and age group on FHI domain scores. A statistically significant multivariate main effect of disorder was observed [Wilks' $\Lambda = .84$, $F(2,55) = 5.31$, $p = .008$, partial $\eta^2 = .16$], indicating that FHI domain scores differed significantly between ASD and ID groups. However, no statistically significant multivariate effect of age group was observed [Wilks' $\Lambda = .98$, $F(2,55) = 0.64$, $p = .533$, partial $\eta^2 = .02$]. The interaction between disorder and age group was also not statistically significant [Wilks' $\Lambda = .96$, $F(2,55) = 1.07$, $p = .351$, partial $\eta^2 = .04$]. These findings indicated that FHI domain scores differed according to disorder, whereas age group and the interaction

between disorder and age group were not statistically significant. The *MANOVA* findings are presented in Table 4.11.

Table 4.11

Results of two-way MANOVA analyses examining the effects of age group and disorder on FHI domain scores

	Wilks' Λ	F	p	Partial η^2
Disorder	.84	5.31	.008	.16
Age group	.98	0.64	.533	.02
Disorder × Age group	.96	0.07	.351	.04

Note. df = 2 for all effects; error df = 55. Wilks' Lambda (Λ) is reported as the multivariate test statistic. Partial η^2 = partial eta squared.

Follow-up univariate analyses were conducted to determine which FHI domain contributed to the observed multivariate effect. Univariate analyses demonstrated a statistically significant main effect of disorder on Domain 1 (Physical) scores [$F(1,56) = 10.64$, $p = .002$]. No statistically significant effect of disorder was observed for Domain 2 (Functional) scores [$F(1,56) = 2.62$, $p = .111$]. Similarly, age group and disorder interaction effects were not statistically significant for either FHI domain (all $p > .05$). These findings indicated that group differences were primarily observed within the Physical domain. The findings of the univariate analysis are presented in Table 4.12.

Table 4.12

Results of univariate analyses (F and p values) for FHI domains

	Domain 1	Domain 2
	F (p)	*F (p)*
Disorder	10.64 (.002)	2.62 (.111)
Age group	0.42 (.519)	1.29 (.260)
Disorder × Age	2.00 (.163)	1.40 (.241)

Note. df = 1 for all effects; error df = 56. Domain 1 = Physical; Domain 2 = Functional.

A two-way ANOVA was conducted to evaluate the effects of age group and disorder on FHI total scores. A statistically significant main effect of disorder was identified [$F(1,56) = 8.62$, $p = .005$, partial $\eta^2 = .13$], indicating that FHI total scores differed significantly across disorder. No statistically significant main effect of age group was observed [$F(1,56) = 0.85$, $p = .360$, partial $\eta^2 = .02$]. The interaction between age group and disorder was also not statistically significant [$F(1,56) = 2.17$, $p = .146$, partial $\eta^2 = .04$]. The ANOVA findings are presented in Table 4.13.

Table 4.13

Results of two-way ANOVA examining effects of age group and disorder on FHI total scores

	F	*p*	Partial η^2
Disorder	8.62	.005	.13
Age group	0.85	.360	.02
Disorder × Age group	2.17	.146	.04

Note. df = 1 for all effects; error df = 56. η^2 = partial eta squared.

These findings indicate that FHI total scores varied significantly according to disorder but did not significantly differ according to age group. Furthermore, no significant interaction between age group and disorder was observed.

Taken together, these findings suggest that although caregivers of children with ASD and ID reported comparable feeding-specific caregiver HRQoL, as reflected by FS-IS-K scores, the nature of feeding difficulties differed between disorders, as reflected by differences in FHI scores, with caregivers of children with ID reporting greater severity of feeding difficulty, particularly within the Physical domain. Therefore, the null hypothesis H_{03} was rejected for the Physical domain and total FHI scores, but retained for the Functional domain and age-group comparisons.

Correlation Between Total FHI Scores and FS-IS-K Scores

Pearson's correlation analysis was conducted to examine the relationship between feeding difficulty severity measured using the FHI and feeding-specific caregiver HRQoL measured using the FS-IS-K subscales and total score across the ASD and ID groups. The null hypothesis H_{04} proposed that there would be no significant relationship between total FHI scores and FS-IS-K scores in the ASD and ID groups.

In the ASD group, weak positive correlations were observed between FHI total scores and FS-IS-K total score (r = .27, p = .191), Subscale 1 – Daily Activities (r = .17, p = .407), Subscale 2 – Worry (r = .20, p = .318) and Subscale 3 – Feeding Difficulties (r = .36, p = .074). Although Subscale 3 demonstrated the highest correlation coefficient among the FS-IS-K subscales, none of the associations reached statistical significance (all $p > .05$). These findings indicated that feeding severity measured using FHI was not significantly associated with feeding-specific caregiver HRQoL in the ASD group.

In the ID group, statistically significant weak positive correlation was observed

between FHI total scores and Subscale 2 – Worry (r = .38, p = .025), whereas moderate positive correlations were observed for Subscale 1 – Daily Activities (r = .47, p = .005), Subscale 3 – Feeding Difficulties (r = .47, p = .005), and the FS-IS-K total score (r = .51, p = .002). All correlations were statistically significant (all $p < .05$), with the FS-IS-K total score, Subscale 1, and Subscale 3 reaching a higher level of significance ($p < .01$).

The positive direction of these correlations indicated that greater feeding severity was associated with higher FS-IS-K scores across domains, reflecting greater feeding-specific caregiver burden and poorer feeding-related QoL. The results of Pearson's correlation analysis are depicted in Table 4.14.

Table 4.14

Results of Pearson's correlation between FHI scores and FS-IS-K scores across ASD and ID groups

FS-IS-K	ASD Group		ID Group	
	Correlation coefficient, *r*	*p*	Correlation coefficient, *r*	*p*
Subscale 1	.17	.407	.47	.005**
Subscale 2	.20	.318	.38	.025*
Subscale 3	.36	.074	.47	.005**
Total score	.27	.191	.51	.002**

Note. Subscale 1 = Daily Activities; Subscale 2 = Worry; Subscale 3 = Feeding Difficulties

** $p < .05$, ** $p < .01$*

Overall, greater feeding severity was associated with poorer feeding-specific caregiver HRQoL in the ID group; however, this relationship was not observed in the ASD group. Thus, the null hypothesis H_{04} was retained for the ASD group, but rejected for the ID group.

Correlation Between Caregiver-Reported Severity of Feeding Difficulties and FS-IS-K Scores

Caregiver-reported severity of feeding difficulties was obtained from the severity rating component of the FHI, wherein caregivers rated the perceived severity of feeding difficulties on a 7-point rating scale. Spearman's rank-order correlation analysis was conducted to examine the relationship between caregiver-reported severity of feeding difficulties and feeding-specific caregiver HRQoL measured using the FS-IS-K subscales and total score across the ASD and ID groups. The null hypothesis H_{05} proposed that there would be no significant relationship between caregiver-reported severity of feeding difficulties derived through FHI and FS-IS-K scores in the ASD and ID groups.

In the ASD group, weak positive correlations were observed between caregiver-reported severity of feeding difficulty and FS-IS-K total score (ρ = .26, p = .205), Subscale 1 – Daily Activities (ρ = .11, p = .581), Subscale 2 – Worry (ρ = .18, p = .373), and Subscale 3 – Feeding Difficulties (ρ = .33, p = .097). Although Subscale 3 demonstrated the highest correlation coefficient among the FS-IS-K domains, none of the associations reached statistical significance (all $p > .05$). These findings indicate that caregiver-reported severity of feeding difficulties was not significantly associated with feeding-specific caregiver HRQoL in the ASD group.

In the ID group, statistically significant moderate positive correlations were observed between caregiver-reported severity of feeding difficulty and FS-IS-K total score (ρ = .53, p = .001), Subscale 1 – Daily Activities (ρ = .48, p = .004), Subscale 2 – Worry (ρ = .48, p = .004), and Subscale 3 – Feeding Difficulties (ρ = .43, p = .012). All correlations were statistically significant (all $p < .05$), with the FS-IS-K total score, Subscale 1, and Subscale 2 reaching a higher level of significance ($p < .01$). The positive direction of the correlations

indicated that greater caregiver-perceived feeding severity was associated with higher FS-IS-K scores across subscales. Since higher FS-IS-K scores reflect greater feeding-specific caregiver burden and poorer feeding-related HRQoL, greater caregiver-perceived feeding severity was associated with greater feeding-specific caregiver impact. The results of Spearman's rank-order correlation analyses are presented in Table 4.15.

Table 4.15

Results of Spearman's rank-order correlation between caregiver-reported feeding severity and FS-IS-K scores across ASD and ID groups

FS-IS-K	ASD Group		ID Group	
	Correlation coefficient, ρ	p	Correlation coefficient, ρ	P
Subscale 1	.11	.581	.48	.004**
Subscale 2	.18	.373	.48	.004**
Subscale 3	.33	.097	.43	.012*
Total score	.26	.205	.53	.001**

Note. Subscale 1 = Daily Activities; Subscale 2 = Worry; Subscale 3 = Feeding Difficulties

** $p < .05$, ** $p < .001$*

Overall, caregiver-perceived feeding severity demonstrated significant associations with feeding-specific caregiver HRQoL among caregivers of children with ID, whereas such relationships were not observed among caregivers of children with ASD. Accordingly, H_{05} was accepted for the ASD group and was rejected for the ID group.

In summary, the FS-IS-K demonstrated excellent test–retest reliability across all subscales and the total score, supporting its consistency as a measure of feeding-specific caregiver HRQoL. The mean total FS-IS-K score indicated a moderate level of feeding-related caregiver burden across the sample, with 'Daily Activities' emerging as the most affected

domain. Severity of disorder did not significantly influence FS-IS-K scores within either the ASD or ID groups. Similarly, neither disorder type nor age group significantly affected FS-IS-K total or subscale scores, suggesting that feeding-specific caregiver HRQoL was broadly comparable across disorder type and age groups. In contrast, FHI scores differed significantly between the ASD and ID groups, with caregivers of children with ID reporting greater feeding difficulty severity, particularly within the Physical domain. Regarding the relationship between feeding severity and caregiver HRQoL, significant positive correlations between FHI scores and FS-IS-K scores were observed in the ID group, indicating that greater feeding severity was associated with poorer feeding-specific caregiver HRQoL. Similarly, caregiver-perceived feeding severity demonstrated significant positive associations with FS-IS-K scores in the ID group. These relationships were not observed in the ASD group, suggesting that the link between feeding severity and caregiver HRQoL may be disorder-specific.

Chapter 5

Discussion

Paediatric feeding disorder (PFD) can have a substantial effect on the caregiver's well-being, in addition to being a feeding or nutrition issue for the child. PFD, which is defined as impaired oral intake that is not age-appropriate and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction (Goday et al., 2019), is more common in children with neurodevelopmental disorders (NDDs) such as Autism Spectrum Disorder (ASD) and Intellectual Disability (ID). Children with NDDs frequently struggle with feeding. According to studies, feeding issues affect approximately 46–89% of children with ASD (Bandini et al., 2010; Ledford & Gast, 2006), and up to 80% of individuals with ID, especially those with more severe impairment (Palmer et al., 1975; Perske, 1977; Ptomey & Wittenbrook, 2015). This places a great deal of pressure on caregivers to manage complex mealtime routines and psychosocial stressors on a daily basis. Given the significant caregiving demands associated with feeding difficulties in children with ASD and ID, it is essential to examine how these challenges affect caregivers' quality of life (QoL).

There is ample evidence of how feeding challenges affect caregivers' QoL. The behavioural and sensory aspects of feeding difficulties unique to ASD and ID (Marshall et al., 2014; Sharp et al., 2013) exacerbate the emotional distress, mealtime anxiety, social isolation, and financial strain that caregivers often report (Silverman et al., 2021). One of the few standardised tools for assessing caregiver health-related quality of life (HRQoL) related to feeding is the Feeding/Swallowing Impact Survey (FS-IS; Lefton-Greif et al., 2014). The lack of a validated feeding-related caregiver QoL measure in Indian languages led to the development of its Kannada adaptation (FS-IS-K; Mathew, 2024). Although the FS-IS-K had already been validated among caregivers of children with cerebral palsy (CP), its relevance to

caregivers of children with ASD and ID (conditions with distinct eating profiles and behavioural presentations) required further investigation. In order to increase the FS-IS-K's clinical value, the present study sought to validate FS-IS-K in this broader neurodevelopmental group. The following discussion addresses the major findings of the study in relation to its objectives.

As part of testing the psychometric properties of FS-IS-K, the test–retest reliability was first examined, followed by the frequency and percentage distribution of caregiver responses on individual FS-IS-K items, comparisons of FS-IS-K scores across severity levels of the disorder, comparisons of feeding-specific caregiver health-related quality of life (HRQoL) across disorders and age groups, differences in feeding difficulty severity as reflected by FHI scores, and the relationships between feeding difficulty severity and caregiver HRQoL. Collectively, these findings are discussed with reference to the clinical validity and applicability of the FS-IS-K among caregivers of children with ASD and ID.

Test–Retest Reliability of the FS-IS-K

The FS-IS-K demonstrated excellent test–retest reliability. Intraclass Correlation Coefficient (ICC) values of the total FS-IS-K score and all subscales were higher than .90, indicating excellent reliability (Koo & Li, 2016). The ICC for the total score was .995, and the ICCs for the subscales were .987 for Daily Activities, .985 for Worry, and .984 for Feeding Difficulties. The results are in line with the reliability reports of other FS-IS versions, including the Turkish FS-IS, with total ICC score of .93 (Serel Arslan et al., 2018), the Brazilian Portuguese version, which reported ICCs ranging from .87 to .95 (Rama et al., 2022), and the Italian FS-IS-IT, which demonstrated excellent test–retest reliability with ICC values > 0.97 (Baffi et al., 2025). High ICCs such as these suggest that caregiver-reported burden of feeding

is temporally stable. This is not surprising, given the chronic and persistent nature of feeding difficulties in ASD and ID (Baraskewich et al., 2021).

ICC values near 1.0 suggest excellent reliability, but require caution in interpretation. Such high values may suggest a small variability in caregiver responses across test administrations. But this is more likely to be due to the stable, long-term nature of feeding-related caregiving demands in this population than item redundancy. This is important for interpreting reliability in chronic conditions, where caregiver burden does not change much over a two-week period, the standard retest interval for patient-reported outcome measures in stable conditions (Mokkink et al., 2010). Similar high ICC values have been reported in validation studies of other caregiver burden measures used with children with chronic conditions, with researchers attributing these findings to the unchanging nature of caregiving rather than measurement problems. The regulatory guidance on patient-reported outcomes also mentions that high test-retest reliability is expected in stable populations, as the construct being measured should not change over the retest interval (Mokkink et al., 2010). Thus, the high ICCs (.95 and above) for the FS-IS-K indicate that the instrument is a reliable measure of the ongoing burden experienced by caregivers of children with NDDs and that there is no problem with the measure itself.

Frequency and Percentage Distribution of Responses on Individual FS-IS-K Items

The mean total score on the FS-IS-K was 53.93 (SD = 16.96), which is about 59.92% of the maximum score. This suggests moderate levels of burden among caregivers of children with ASD and ID. The mean item score of 3.00 indicated a significant decline in caregiver HRQoL, which was consistent with the original FS-IS validation study (Lefton-Greif et al., 2014) and the Kannada adaptation by Mathew (2024), which reported a mean item score of 2.54 among caregivers of children with CP. The slightly elevated mean score in the present

study may be reflective of the specific caregiving needs of ASD and ID, with sensory-based food aversions, behavioural feeding problems and cognitive limitations adding distinct dimensions to caregiving burden (Bandini et al., 2010; Rezaei et al., 2011).

Subscale 1, measuring the impact on activities of daily living, had the highest mean percent score (M = 16.62, SD = 5.65; 66.48% of the maximum possible score of 25), followed by Subscale 2, measuring caregiver-related worry (M = 21.22, SD = 7.06; 60.63% of the maximum possible score of 35), and Subscale 3, measuring feeding-related difficulties (M = 16.10, SD = 6.28; 53.67% of the maximum possible score of 30). This subscale profile is of clinical significance. This suggests that the practical disruption to everyday life was the heaviest burden for the caregivers, with psychological worry not far behind. The feeding difficulties themselves, although still considerable, contributed comparatively less to the overall burden. Importantly, this pattern indicates that the burden of caregiving is not confined to the feeding interaction, but rather is embedded in the daily routine and produces persistent psychological distress. This resonates with the wider literature which emphasises that caregivers of children with feeding difficulties frequently face disruption of family routines, reduced involvement in social activities and significant emotional distress that extends to different spheres of life (Hatzmann et al., 2009; Lefton-Greif et al., 2014; Rama et al., 2022).

Subscale 1 — Daily Activities

Of the three subscales, findings from Subscale 1 revealed that feeding-related difficulties had a significant impact on daily activities of caregivers. The impact on family outings and eating outside of the home (Item 4) was most frequently endorsed (63.3% answered “Very Often” or “Almost Always”). This finding is in line with the broader literature indicating that feeding problems frequently disrupt family routines and reduce social participation (Hatzmann et al., 2009; Lefton-Greif et al., 2014; Rama et al., 2022). This is especially true in

the Indian context, where the inability to eat out or participate in social meals is an important aspect of social life, and thus exacerbates the social isolation experienced by these caregivers.

High endorsement was observed for Item 3, which indicated reluctance to leave the child with others because of safety concerns related to feeding (35.0% selecting "Almost Always"), and Item 5, which reflected caregiver fatigue related to managing feeding responsibilities. These findings are corroborated by the literature indicating that caregivers of children with feeding difficulties often experience physical exhaustion and few opportunities for respite (Reis et al., 2020; Winston et al., 2010). Consistent with the present findings, Yap et al. (2025) also found that the continuous demands of adapting meals and supervising feeding caused emotional exhaustion for caregivers.

A significant group difference was found for item 1, reflecting the impact of feeding difficulties on the daily routine. Caregivers of children with ID endorsed higher response categories more often (38.2% endorsed “Very Often”) while caregivers of children with ASD most often endorsed “Never” (30.8%). This divergence may be a reflection of the nature of feeding difficulties associated with each condition. With ID, deficits in self-feeding, poor oral-motor coordination, and increased need for caregiver assistance for basic feeding tasks (Linscheid, 1983; Rezaei et al., 2011) may cause a more pervasive disruption to daily caregiving routines. However, caregivers of children with ASD, who are highly burdened, may have adapted their child’s specific food preferences and rituals into their routines, leading to more predictable but limited daily feeding routines (Schreck et al., 2004; Twachtman- Reilly et al., 2008).

Subscale 2 — Worry

Within the worry subscale, worries about the child’s overall health (Item 6) was the most prominent item endorsed across both groups with 75.0% of caregivers endorsing “Very

Often" or "Almost Always". This result is consistent with the findings of the South African adaptation of FS-IS (Bestenbier, 2021) where concerns about the general health of the child were among the most reported. It is also consistent with the known association between paediatric feeding difficulties and poor health outcomes, including malnutrition, growth failure and recurrent respiratory illness (Andrew & Sullivan, 2010; Godays et al., 2019; Rogers & Arvedson, 2005). The health-related issues may be further aggravated in the Indian context particularly where malnutrition is a major public health problem.

Item 7 (concerns about the adequacy of the child's food intake) was also endorsed to a considerable degree (60.0%) indicating caregivers' persistent anxiety about whether their child received adequate nutrition. This is especially important as children with ASD and ID are at risk of nutritional deficiencies due to food selectivity, restricted variety in their diet and refusal behaviours (Cermak et al., 2010; Marshall et al., 2014; Rezaei et al., 2011). Davis et al. (2003) and Silver et al. (1998) found a positive association between perceived caregiving difficulty and maternal depression. Persistent health and nutrition related worries captured by these items may have wider implications for caregiver mental health.

Item 9, reflecting concerns about choking or breathing problems during feeding, was the least endorsed item in both groups, with 65.0% of caregivers endorsing "Never" or "Almost Never." This finding is somewhat different from studies of children with CP where aspiration risk and pharyngeal dysphagia are major clinical concerns (Serel Arslan et al., 2018; Mokhlesin et al., 2024). The lower endorsement in the present sample is consistent with the nature of feeding difficulties in ASD and ID, which are more often characterised by behavioural and sensory-based difficulties, rather than structural or neuromotor swallowing problems (Dodrill & Gosa, 2015; Lefton-Greif, 2008). However, it is interesting to note that a higher percentage of caregivers of children with ID (29.4%) endorsed choking or breathing concerns than those with ASD (7.7%). Notably, 14.7% of caregivers of children with ID endorsed "Almost Always"

for this item, compared to none of the ASD caregivers. This is in line with the findings that children with more severe cognitive and motor impairments, such as children with Down syndrome and moderate to severe ID, are more likely to have oral-motor dysfunction and aspiration risk (İslamoğlu et al., 2024; Rezaei et al., 2011).

Concerns about impact on other family members (item 12) was also relatively low (30.0%), although this does not detract from its clinical importance. The broader literature suggests that ripple effects of feeding difficulties are frequently reported to impact family functioning, such as disrupted family meals, sibling distress and reduced family social participation (Hatzmann et al., 2009; Lefton-Greif et al., 2014). Caregivers may prioritise immediate child-focused concerns over broader family impacts, which may explain the relatively lower endorsement of this item, or families may have adapted to fit the feeding needs of the child within family routines.

Subscale 3 — Feeding Difficulties

The item with the highest endorsement across all items in Subscale 3 was not knowing how long the child's feeding difficulties will last or persist (Item 16; 50.0%). The next highest item was differing opinions regarding feeding management by family and other professionals (Item 17; 46.7%). These findings are consistent with the reports of Mathew (2024) and Bestenbier (2021) in which conflicting advice from family members and professionals and uncertainty regarding prognosis were identified as key sources of caregiver distress. In the Indian family setting, feeding decisions are often influenced by input from extended family members, and caregivers frequently have to deal with competing cultural expectations, traditional feeding practices and professional recommendations. This may in particular inflate the burden captured by item 17.

Caution should be used when interpreting the relatively low endorsement of Item 14, which reflects difficulty in preparing food that meets the child's specific feeding requirements (50.0% endorsing "Never"). We take this item to reflect the practical difficulty that caregivers experience in knowing how to prepare food appropriately for their child's needs in terms of texture modification, presentation, or highly selective preferences, rather than indicating difficulty in accessing formal services. The relatively low endorsement may be indicative of a subset of caregivers having become familiar with their child's specific requirements over time, and having established workable feeding routines, even if these are restrictive. However, it may also be a sign of an unrecognised gap between what they are providing and what would be clinically appropriate for their child. This finding was supported by Yap et al. (2025) who reported that caregivers often used trial-and-error strategies and ongoing meal adjustments to accommodate their child's feeding preferences, particularly regarding texture, presentation and brand. Such accommodations may decrease mealtime distress in the short term, but may encourage restrictive eating patterns and contribute to long-term nutritional problems (Cermak et al., 2010; Marshall et al., 2014). The relatively greater endorsement of this item among ID caregivers than ASD caregivers further suggests that uncertainty regarding appropriate food preparation may be more salient when feeding difficulties are accompanied with oral-motor deficits and swallowing concerns, as more commonly observed in children with ID (Rezaei et al., 2011).

The least endorsed item in Subscale 3 was Item 15, which reflects the difficulty caregivers experience when others provide food items that are not suitable for their child. Overall, 60.0% of caregivers selected "Never" or "Almost Never." A particularly interesting group difference was found here, with 76.9% of ASD caregivers endorsing "Never" or "Almost Never" compared to 47.0% of ID caregivers. This finding may suggest that caregivers of children with ASD may have been able to set clearer boundaries and make their child's specific

food needs clearer to others around them over time. This may be because of the highly predictable and rigid nature of food preferences in ASD, which makes it easier to set and enforce boundaries (Schreck et al., 2004; Twachtman-Reilly et al., 2008). Alternatively, the social network of these caregivers may have become sufficiently aware of the child's selective eating patterns to avoid offering inappropriate foods. On the other hand, the relatively higher endorsement among caregivers of children with ID may relate to the more ambiguous and variable nature of feeding difficulties among this population, which may make it more difficult for others to consistently identify and offer appropriate food items (Rezaei et al., 2011). This finding also has broader social implications in terms of the challenges faced by caregivers in managing their child's feeding needs within extended family settings and social gatherings where food sharing is culturally significant in India, and declining or redirecting offered food may carry social tension.

Comparison of FS-IS-K Scores Across Severity Levels of the Disorder

Mann–Whitney U analyses showed no significant differences in FS-IS-K total or subscale scores between the mild and moderate severity groups in either the ASD or ID samples (all $p > .05$), resulting in the acceptance of H_{01} that stated that there would be no significant difference in FS-IS-K scores between caregivers of children with mild and moderate severity of ASD and ID. Within the ASD group, severity level did not significantly influence Subscale 1 (Daily Activities) scores ($|Z| = 0.09$, $p = .927$), Subscale (Worry) scores ($|Z| = 0.34$, $p = .737$), Subscale 3 (Feeding Difficulties) scores ($|Z| = 1.47$, $p = .143$), or total FS-IS-K scores ($|Z| = 0.70$, $p = .484$). Similarly, within the ID group, no statistically significant differences were observed between mild and moderate severity levels for Subscale 1 (Daily Activities) ($|Z| = 0.39$, $p = .700$), Subscale 2 (Worry) scores ($|Z| = 0.34$, $p = .737$), Subscale 3 (Feeding Difficulties) ($|Z| = 1.86$, $p = .063$), or total FS-IS-K scores ($|Z| = 0.79$, $p = .430$). These results imply that the clinical severity of the underlying neurodevelopmental impairment in this

population does not significantly affect feeding-specific caregiver HRQoL as assessed by the FS-IS-K.

Given the larger body of research, which has typically documented correlations between caregiver burden and severity of the disorder in neurodevelopmental populations, this finding is somewhat unexpected. Ten Hoopen et al. (2020) found that among children with the highest comorbid burden, both child and primary caregiver HRQoL were notably lower, suggesting that the severity of associated problems can compound caregiving impact, while Suresh et al. (2014) discovered that caregivers of children with both ASD and ID reported higher burden than those caring for children with ID alone. There are, however, several methodological and contextual reasons that may explain this null finding. First, the small sample sizes of the subgroups (mild ASD: n = 20, moderate ASD: n = 6; mild ID: n = 27, moderate ID: n = 7) reduced statistical power substantially and may have missed true differences between the groups. Second, as noted by Vaz et al. (2021), variables that were not measured in the present study (e.g., family support networks and coping mechanisms) may moderate the relationship between disorder severity and caregiver QoL. Third and probably most importantly, the present research finding suggests that regardless of the actual severity rating of the disorder, even mild-to-moderate feeding difficulties associated with NDDs are enough to place a great burden across caregiver HRQoL domains. The similar median FS-IS-K total scores across severity subgroups in both disorders (ASD mild: 50.00, ASD moderate: 51.00; ID mild: 61.00, ID moderate: 62.00) support this conclusion, showing a consistently high burden profile across severity levels. Fourth, it is important to note that the present sample included only children classified as mild or moderate severity of ASD and ID; children with severe disorders were not represented in the sample. This narrow range of severity may have also limited the ability to detect meaningful differences in caregiver HRQoL across severity levels, as the full range of burden associated with severe neurodevelopmental impairment was

not captured. However, the few studies that have found significant relationships between disorder severity and caregiver burden have tended to recruit samples with the full range of severity, including severe classifications (Eisenhower et al., 2005; Totsika et al., 2011). The absence of a severe subgroup in the present study, therefore, constitutes a meaningful sampling limitation that should be considered when interpreting the null finding. This finding has clinical implications, suggesting that even caregivers of children with mild severity of disorder may benefit from targeted support and intervention, and that identifying caregivers at risk for increased feeding-related burden may require more than severity of disorder-based screening.

Comparison of FS-IS-K Scores Across the Disorder and Age groups

Two-way MANOVA revealed no statistically significant multivariate main effect of disorder [Wilks' $\Lambda = .95$, $F(3,54) = 0.87$, $p = .464$, partial $\eta^2 = .05$], age group [Wilks' $\Lambda = .99$, $F(3,54) = 0.27$, $p = .845$, partial $\eta^2 = .02$], or their interaction [Wilks' $\Lambda = .99$, $F(3,54) = 0.20$, $p = .899$, partial $\eta^2 = .01$] on FS-IS-K subscale scores, leading to the acceptance of H_{02}, which stated that there would be no significant difference in FS-IS-K scores between caregivers of children with ASD and caregivers of children with ID, or between caregivers of younger children (2–6 years) and caregivers of older children (6–12 years). Follow-up univariate analyses confirmed no significant main or interaction effects for any individual subscale (all $p > .05$). Similarly, the two-way ANOVA for total FS-IS-K scores revealed no significant main effect of disorder [$F(1,56) = 2.34$, $p = .131$, partial $\eta^2 = .04$], age group [$F(1,56) = 0.75$, $p = .391$, partial $\eta^2 = .01$], or their interaction [$F(1,56) = 0.05$, $p = .831$, partial $\eta^2 = .00$]. The trivial partial η^2 values across analyses also supported the conclusion that feeding-related caregiver burden was similar across the disorder and age groups in this sample, suggesting that these non-significant results also reflected negligible practical differences between groups.

Children with ID can have oral motor dysfunctions, impaired swallowing coordination, and nutritional deficits (Anil et al., 2019), whereas children with ASD often present with increased food selectivity, sensory aversions, and ritualistic feeding behaviours (Bandini et al., 2010; Cermak et al., 2010; Visvalingam & Sivanesom, 2024). Despite these mechanistic differences, these current findings suggest that the cumulative impact on caregiver HRQoL across the domains of daily activities, worry and feeding-related stress is broadly similar across the two disorders. This is noteworthy given that there is considerable variability in feeding profiles in the literature between individuals with ASD and ID (Ptomey & Wittenbrook, 2015). It is in line with the more general observation that in neurodevelopmental groups, caregiver burden is more closely associated with the practical demands of caregiving, especially those related to managing nutrition, than with specific diagnostic characteristics (Craig et al., 2003; Winston et al., 2010). From a clinical perspective, the findings of the present study validate the use of the FS-IS-K as a diagnostically inclusive instrument that can capture feeding-related caregiver burden across NDDs. Importantly, while Gent et al. (2024) used the FS-IS (Lefton-Greif et al., 2014) to measure caregiver burden in feeding difficulties of autistic children, their study was not a formal validation of the tool in an ASD population. Although Baffi et al. (2025) included caregivers of children with developmental disorders as a comparison group in the Italian validation, no previous FS-IS validation study has focused specifically on caregivers of children with ASD or ID as the primary study population. The present study thus extends validation evidence of the FS-IS-K to a broader neurodevelopmental population, further emphasising its clinical utility across NDDs. Therefore, this is the first study to systematically validate the FS-IS-K in caregivers of children with ASD and ID, further emphasising the clinical utility of the FS-IS-K in a broader neurodevelopmental population.

In terms of age effects, caregivers of younger children (ages 2–6) had higher FS-IS-K mean scores than those of older children (ages 6–12) in both groups; however, this tendency

was not statistically significant. The directional pattern aligns with previous research that suggests younger children with feeding difficulties may require more caregiving because of the intensity of early intervention requirements and their increased reliance on adult assistance during mealtimes (Borowitz & Borowitz, 2018; Crasta et al., 2014). However, the present findings were not statistically significant. Hence, conclusions on age-related differences in FS-IS-K scores should be interpreted with caution. Further studies with larger samples stratified by age are needed to explore the relationship between child age and caregiver feeding-related burden.

Comparison of FHI Scores across the Disorder and Age Groups

Although FS-IS-K scores were comparable across disorder and age groups, further analyses examined whether the nature and severity of feeding difficulties, as measured by the FHI, differed between groups, addressing H_{03}, which stated that there would be no significant difference in FHI scores (Physical domain, Functional domain, and total scores) between children with ASD and ID and between younger (2–6 years) and older children (6–12 years). In the current study, only the Physical and Functional domains were assessed, as these domains are indicative of observable feeding and swallowing difficulties and feeding performance, which are more directly linked to caregiver-reported feeding impact. Analyses of FHI scores showed a significant main effect of the disorder on the Physical domain [$F(1,56) = 10.64$, $p = .002$] and on total FHI scores [$F(1,56) = 8.62$, $p = .005$, partial $\eta^2 = .13$], with ID caregivers reporting higher FHI scores than ASD caregivers. No statistically significant effect of disorder was observed for Domain 2 (Functional) scores [$F(1,56) = 2.62$, $p = .111$], suggesting that group differences were primarily confined to the physical dimensions of feeding difficulty. There was no significant effect of age group or disorder and age group interaction for either FHI domain scores or total scores (all $p > .05$). However, descriptive statistics revealed that in the ASD group, younger children had higher FHI total scores than older children ($M = 23.54$

vs. $M = 18.38$), whereas FHI scores in the ID group were broadly similar across age groups ($M = 26.68$ vs. $M = 27.87$). Although this difference was not statistically significant, the directionality may suggest that the physical dimensions of feeding difficulty in ASD decrease somewhat with age, possibly reflecting the impact of early intervention or developmental maturation, while the severity of feeding difficulty in ID seems to be more stable across this age range. Further studies with larger samples are needed to examine this pattern. These results suggest that the subjective burden of caregiving related to feeding difficulties may be similar in general between the two groups (as shown by the FS-IS-K scores), but the objective characteristics and severity of feeding difficulties (especially in the Physical domain of FHI) are significantly different between the two populations.

For the present study, only the Physical and Functional domains were assessed, as these domains reflect observable feeding and swallowing difficulties and feeding performance, which are more directly related to caregiver-reported feeding impact. The higher FHI Physical domain scores in the ID group are in line with research showing that children with ID exhibit a higher prevalence of oral motor dysfunction, dysphagia, and structural feeding impairments, in contrast to children with ASD, whose feeding difficulties are more frequently behaviourally and sensorially mediated (Andrew & Sullivan, 2010a; Anil et al., 2019; Shabnam & Swapna, 2023). Even when general caregiver burden instruments produce comparable scores across groups, this distinction highlights the necessity of population-specific clinical assessment approaches. H_{03} was rejected for the Physical domain and total FHI scores and accepted for the Functional domain, while H_{03} was accepted for all age group comparisons.

Correlation Between FHI Scores and FS-IS-K Scores

Pearson's correlation analysis addressed H_{04}, which stated that there would be no significant relationship between total FHI scores and FS-IS-K scores in the ASD and ID group.

In the ID group, greater feeding severity measured by the FHI was significantly and positively linked with higher FS-IS-K scores throughout the total and subscale scores (r = .38–.51, all p < .05), leading to the rejection of H_{04} for the ID group. In contrast, no statistically significant correlations were observed in the ASD group (r = .17–.36, all p > .05), resulting in the acceptance of H_{04} for ASD group. Notably, Subscale 3 (Feeding Difficulties) demonstrated the highest correlation coefficient in this group (r = .36, p = .074), representing a trend approaching significance that may warrant further exploration in larger samples. Spearman's rank-order correlation analyses examining caregiver-reported severity of feeding difficulties addressed H_{05}, which stated that there would be no significant relationship between caregiver-reported severity of feeding difficulties, derived through FHI, and FS-IS-K scores in the ASD and ID groups. A parallel pattern was observed. Significant positive correlations were observed between caregiver-perceived severity and FS-IS-K scores in the ID group (ρ = .43–.53, all p < .05), while no significant associations were found in the ASD group (ρ = .11–.33, all p > .05), with Subscale 3 again demonstrating the highest coefficient (ρ = .33, p = .097), consistent with the directional pattern observed in the Pearson's analysis.

The significant associations between feeding severity and caregiver HRQoL in the ID group are consistent with studies reporting a direct association between the severity of a child's functional impairments and the burden experienced by their caregivers (Sullivan et al., 2000; Rezaei et al., 2011). For example, greater physical severity in children with ID may be more directly related to increased time spent caregiving, greater physical demands during mealtimes, and greater concern regarding nutritional outcomes, all of which may lead to decreased caregiver QoL. Feeding difficulties in children with ID often also reflect underlying neuromotor and structural impairments (Anil et al., 2019). Significant associations between feeding difficulty severity and caregiver HRQoL were also reported by Dalpatadu et al. (2025) in a South Asian sample, lending cross-cultural support to the present findings.

The lack of significant correlations in the ASD group should be interpreted with caution. One explanation may be that feeding difficulties in children with ASD are predominantly behavioural and sensory, and may not be adequately captured by a severity measure that is physical in nature, such as the FHI. The relatively small sample size of ASD (n = 26) may also have limited the statistical power to identify modest associations between feeding severity and caregiver HRQoL, especially as the correlation coefficients observed were positive and weak to moderate in magnitude. Thus, the lack of statistical significance should not be interpreted as conclusive evidence of the absence of a relationship, but rather the relationship may be weaker, more complex, or underpowered to be detected in this sample. Feeding difficulties in ASD have been consistently described as being characterised by food selectivity, texture rejection and mealtime rigidity, driven by sensory sensitivity and ritualistic behaviour (Baraskewich et al., 2021; Cermak et al., 2010; Sharp et al., 2013) and not by structural or neuromotor impairments. Consequently, the FHI, which emphasises physical and functional feeding handicap, may not fully reflect the dimensions of feeding difficulty that most directly impact caregiver HRQoL in this population. Moreover, as noted by Thullen & Bonsall (2017), caregiver stress in ASD is influenced by a broad constellation of factors beyond the severity of feeding difficulties alone, including social isolation, co-parenting conflict, and behaviour management challenges, which may dilute or obscure the direct relationship between feeding severity and HRQoL in this group.

This differential pattern of association across groups has important implications for clinical practice. It suggests that for caregivers of children with ID, addressing the severity of the child's feeding difficulties may have a direct and measurable impact on caregiver HRQoL, making feeding intervention a high-priority target in this group. For caregivers of children with ASD, however, addressing feeding severity alone may be insufficient; broader family-centred support addressing the emotional, social, and behavioural dimensions of feeding management

may be equally or more important. These findings resulted in the rejection of H_{04} and H_{05} for the ID group and acceptance of H_{04} and H_{05} for the ASD group, indicating a disorder-specific pattern in the association between feeding severity (both FHI-based and caregiver-reported) and caregiver HRQoL.

Overall, the findings of the present study support the applicability of the FS-IS-K as a reliable and clinically meaningful measure of feeding-related caregiver HRQoL among caregivers of children with ASD and ID. Although feeding difficulties manifested differently across disorders, caregivers reported comparable levels of burden, particularly in relation to worry, daily functioning, and uncertainty surrounding feeding outcomes. The findings further suggest that caregiver burden cannot be fully explained by feeding severity alone and is shaped by broader psychosocial and contextual factors. These findings should, however, be interpreted in light of the relatively modest sample size and the absence of participants with severe ASD or ID. Collectively, these findings provide support for the use of the FS-IS-K in clinical and research settings to identify caregiver needs, guide the planning of family-centred interventions, and facilitate the evaluation of feeding-related outcomes in Kannada-speaking populations.

Chapter 6

Summary and conclusions

Paediatric Feeding Disorder (PFD) is a multifaceted condition that goes far beyond the child's feeding difficulties and places substantial physical, emotional, and social demands on caregivers. Children with neurodevelopmental disorders (NDDs) including Autism Spectrum Disorder (ASD) and Intellectual Disability (ID) are particularly susceptible to feeding difficulties with prevalence estimates ranging from 46-89% in ASD (Bandini et al., 2010; Ledford & Gast, 2006) and up to 80% in ID (Palmer et al., 1975; Perske, 1977). On a daily basis, the complex mealtime behaviours, nutritional needs and psychosocial stressors associated with these conditions and their management place a significant burden on caregivers, impacting their health-related quality of life (HRQoL) in the areas of daily activities, emotional well-being and social participation.

While tools to assess caregiver quality of life in paediatric disability are available internationally, validated measures specifically addressing feeding-related caregiver HRQoL remain limited. The Feeding/Swallowing Impact Survey (FS-IS; Lefton-Greif et al., 2014)was developed to capture the impact of children's feeding and swallowing difficulties on caregiver HRQoL across three domains: daily activities, worry, and feeding difficulties. Its Kannada adaptation, the FS-IS-K (Mathew, 2024), was previously validated only among caregivers of children with Cerebral Palsy (CP). Therefore, to extend the clinical validation of the FS-IS-K the questionnaire was administered on caregivers of children with ASD and ID.

The study employed an analytical cross-sectional research design. Sixty primary caregivers of children aged 2–12 years diagnosed with Pediatric Feeding Disorder secondary to ASD (n = 26) or ID (n = 34) were recruited from the Department of Clinical Services and Department of Special Education at the All India Institute of Speech and Hearing (AIISH),

Mysuru, and from special schools in Mysuru. Caregivers who were 18 years or above and able to read Kannada were included; those with significant health issues, psychiatric illnesses, or prior feeding intervention experience were excluded. Socioeconomic status was determined using the modified Kuppuswamy scale (Mandal & Hossain, 2025). The study was conducted in two phases.

In Phase I, clinical validation was conducted by administering the FS-IS-K. To examine the severity of feeding difficulty and understand the relationship between feeding difficulty severity and caregiver HRQoL, the Feeding Handicap Index (FHI; Shabnam & Swapna, 2023) was additionally administered. For the present study, only the Physical and Functional domains of the FHI were assessed, as these domains reflect observable feeding and swallowing difficulties and their impact on feeding performance, which are conceptually most aligned with the caregiver burden related to feeding difficulties reflected in the FS-IS-K. In Phase II, test–retest reliability was assessed by re-administering the FS-IS-K to 20% of participants after two weeks.

Statistical analyses were conducted using IBM SPSS (Version 26). Normality was assessed using the Shapiro–Wilk test. Descriptive statistics and frequency distributions were computed for individual items of FS-IS-K. Mann–Whitney U tests were used to compare FS-IS-K scores across severity subgroups. Two-way MANOVA and ANOVA examined the effects of disorder and age group on FS-IS-K subscale and total scores, as well as FHI scores. Pearson's correlation examined the relationship between total FHI scores and FS-IS-K scores, while Spearman's rho assessed the relationship between caregiver-reported feeding severity and FS-IS-K scores. Test–retest reliability was established using the Intraclass Correlation Coefficient (ICC), computed using a two-way mixed-effects model with absolute agreement.

The FS-IS-K exhibited excellent test-retest reliability. There was excellent reliability (ICC = .995) for the total score and the three subscales (Daily Activities ICC = .987, Worry ICC = .985, and Feeding Difficulties ICC = .984) with ICC values above the accepted value of .90 (Koo & Li, 2016), supporting the temporal stability of the measure over a two-week period.

The mean total FS-IS-K score was 53.93 (*SD* = 16.96), with an average item score of 3.00, indicating moderate levels of feeding-related caregiver burden across the sample. Subscale 1 (Daily Activities) had the highest mean percent (66.48%) of the three subscales. Within Subscale 1 (Daily Activities), Item 4 (impact of feeding difficulties for family outings and eating outside the home) received the highest overall endorsement (63.3%), although this item was endorsed significantly more by ID caregivers (73.5%) than by ASD caregivers (50.0%). A significant group difference was also found for Item 1, where the modal response was "Never" for ASD caregivers (30.8%), but "Very Often" for ID caregivers (38.2%). Within Subscale 2 (Worry), the single most endorsed item across the entire questionnaire was Item 6 (concern about the child's overall health) (75.0%), followed closely by Item 7 (adequacy of food intake) (60.0%). The least endorsed items were Item 9 (worry about choking or breathing difficulties) and Item 12 (impact on family members), although ID caregivers were more concerned about choking than their ASD counterparts. In Subscale 3 (Feeding Difficulties), Item 16 (uncertainty about duration and persistence of feeding difficulties) was the most endorsed (50.0% across both groups), followed by Item 17 (conflicting advice from professionals and family; 46.7%); Items 14 and 15 (difficulty in preparing suitable foods and managing unsuitable foods provided by others) were the least endorsed overall, although ID caregivers endorsed Item 15 considerably more than ASD caregivers (35.3% vs. 15.3%), suggesting greater concern about dietary variety in the ID group.

The Mann-Whitney U analyses did not show any statistically significant differences between the mild and moderate severity subgroups on the total or subscale scores of the FS-

IS-K for ASD or ID. The median total scores were generally similar across severity levels within each disorder. These results suggest that even mild-to-moderate severity levels of NDDs are sufficient to generate significant feeding-related caregiver burden and that severity of the disorder is not the only determinant of degree of feeding-specific caregiver HRQoL impact. However, it is important to note that the sample did not include children with severe ASD or ID, which may have limited the ability to detect a severity gradient across the full spectrum of impairment.

Two-way MANOVA and ANOVA analyses revealed no significant main effects of disorder or age group on FS-IS-K subscale or total scores, nor significant interactions of these factors. These findings indicate that the disorder and age group have a similar impact on feeding-specific caregiver HRQoL in this sample. To further examine the severity of feeding difficulty in the care recipients, FHI scores were compared between disorder and age groups. FHI analyses revealed a significant main effect of disorder on the Physical domain ($p = .002$) and total FHI scores ($p = .005$), with the ID group scoring higher than the ASD group. The discordant pattern of FHI and FS-IS-K results suggests that clinician-rated feeding severity and caregiver-reported HRQoL assess different but complementary constructs, both of which are necessary to fully understand feeding-related caregiver burden.

Pearson's correlation analysis showed significant moderate positive correlations between FHI total scores and FS-IS-K scores for all subscales and the total score in the ID group, suggesting that higher feeding severity was associated with lower feeding-specific caregiver HRQoL. In the ASD group, no significant associations were found with Subscale 3 (Feeding Difficulties) having the highest coefficient in this group ($p = .074$), which approached but did not reach significance. Similar patterns were observed in Spearman's rank-order correlation analyses. Significant positive correlations between caregiver-reported feeding severity and FS-IS-K scores were observed in the ID group for all the subscales and the total

score. No significant correlations were found in the ASD group. The lack of substantial correlations in the ASD group probably reflects the predominantly behavioural and sensory nature of feeding difficulties in ASD that may not be sufficiently captured by a physically-oriented severity measure such as the FHI.

The results of this study support the following conclusions. First, the FS-IS-K showed excellent test-retest reliability for caregivers of children with ASD and ID, supporting the temporal stability and consistency of the measure in this population. Second, caregivers of children with ASD and ID reported moderate levels of feeding-specific caregiver burden. Daily Activities subscale showed the greatest impact. Third, the severity of the disorder did not significantly impact FS-IS-K scores, suggesting that caregiver burden related to feeding is present even at milder levels of severity. However, this finding should be interpreted cautiously due to small subgroup sizes and the exclusion of children with severe disorders, which may have limited the range of severity to detect a gradient. Fourth, no significant differences were found in feeding-specific caregiver HRQoL across disorders or age groups, which suggests that the FS-IS-K provides a consistently elevated burden profile across these variables. Fifth, the severity of feeding difficulties differed significantly between the ASD and ID groups, with greater Physical domain impairment in the ID group. Sixth, feeding severity correlated significantly with caregiver HRQoL specific to feeding in the ID group but not in the ASD group, reflecting the different mechanisms of feeding difficulties across the two conditions. Collectively, these findings provide preliminary evidence for the reliability and clinical validity of the FS-IS-K in Kannada-speaking caregivers of children with ASD and ID, and extend its clinical utility beyond the CP population in which it was originally validated.

Clinical Implications

1. The FS-IS-K is a validated caregiver-reported outcome measure in Kannada that can be used by speech-language pathologists to screen and quantify feeding-related caregiver burden in families of children with NDDs.
2. FS-IS-K scores indicated moderate levels of feeding-related caregiver burden across disorders and age groups; thus, feeding-related caregiver burden should be routinely assessed in caregivers of children with NDDs regardless of diagnosis, age or severity. The results also indicate that caregiver HRQoL should be viewed as a distinct clinical domain and should be routinely assessed in the context of paediatric feeding assessment, rather than being merely inferred from child-related variables.
3. The strong relationship between severity of feeding and caregiver HRQoL in the ID group suggests that early and evidence-based feeding interventions may not only improve the feeding outcomes in children but also improve the well-being of caregivers, though this requires prospective investigation
4. The high frequency of concerns expressed by caregivers about their child's health and feeding prognosis highlights the need for clear counselling, caregiver education and ongoing professional support throughout the intervention process.
5. The FS-IS-K may be used as an outcome measure to monitor changes in feeding-related caregiver HRQoL following intervention and to evaluate the effectiveness of feeding management programs, and as a clinical tool to identify families who need extra support and facilitate appropriate interdisciplinary referrals (e.g., to psychologists, nutritionists, social workers, and feeding specialists).

Limitations

1. The total sample size (N = 60) was sufficient for the primary analyses, but the subgroup sample sizes were small for comparisons of severity (moderate ASD: n = 6; moderate ID: n = 7), limiting statistical power and possibly reducing the ability to detect significant between-group differences. Thus, caution should be exercised in interpreting results regarding severity.
2. The sample was limited to children with mild and moderate ASD and ID, and did not include children with severe neurodevelopmental impairment. Thus, the results may not be representative of the full range of feeding-related caregiver burden associated with more severe conditions.
3. Participants were recruited from a single tertiary-level institution and special schools at Mysuru city. Hence, the findings may not be generalisable to caregivers from different regions, rural settings or Kannada-speaking populations with varied socio-economic and cultural backgrounds.
4. A number of variables related to caregivers and children, such as caregiver education, family type, socioeconomic status, gender of the child, dependency status and age at which feeding difficulties were identified, could not be analysed because the sample size in the sub-groups was too small. Hence, the potential influence of these factors on feeding-specific caregiver quality of life remains unknown.
5. The study included only the physical and functional domains of FHI. Feeding difficulties in children with ASD are often behaviourally and sensorily driven. The FHI may not capture all aspects of feeding that are most relevant to caregiver HRQoL.
6. The sample of caregivers is dominated by females (58 of 60 participants), reflecting the dominant models of care giving, but limiting the representation of male caregivers' perspectives.

7. The FS-IS-K is a self-administered questionnaire and needs Kannada literacy, limiting its applicability among caregivers with lower literacy levels and restricting its use in certain clinical and community settings.

Future Directions

1. Future studies should include larger, more diverse samples, including children with varying severity of NDDs, to improve the generalizability of findings and to enable subgroup analyses across age, severity, socioeconomic status, and other demographic variables.
2. Longitudinal studies are needed to understand the trajectory of feeding-related caregiver HRQoL over time, and to identify factors associated with changes in caregiver outcomes over the course of a child's feeding difficulties.
3. The adaptation and validation of the FS-IS in additional Indian languages, as well as the development of clinician-administered versions would make the tool more accessible and applicable across the various linguistic and literacy groups.
4. Research is needed to investigate the association between feeding-related caregiver HRQoL and more general caregiver outcomes, including psychological well-being, stress, caregiver burden and burnout, to better understand the broader influence of paediatric feeding difficulties on family systems.
5. There is a need to explore caregiver-targeted interventions such as psychoeducation, feeding management training, mealtime coaching, and peer-support programmes to understand their effectiveness in improving caregiver HRQoL and reducing feeding-related burden.
6. Future research should examine the sensitivity of the FS-IS-K to intervention-related changes, to establish its utility as an outcome measure for monitoring treatment efficacy over time.

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Appendix 1

AIISH Institute Review Board Report

All India Institute of Speech and Hearing
(An autonomous Institute under the
Ministry of Health and Family Welfare, Govt. of India)
Center of Excellence - Assessed & Accredited by NAAC with 'A' Grade
ISO 9001:2015 Implemented Institute
Manasagangothri, Mysuru-570006

ಅಖಿಲ ಭಾರತ ವಾಕ್ ಮತ್ತು ಶ್ರವಣ ಸಂಸ್ಥೆ
ಮಾನಸಗಂಗೋತ್ರಿ, ಮೈಸೂರು-570006
अखिल भारतीय वाक् श्रवण संस्थान
मानसगंगोत्री, मैसूरु - 570 006

INSTITUTE REVIEW BOARD (IRB) APPROVAL FOR BIO-BEHAVIOURAL RESEARCH PROPOSAL INVOLVING HUMAN SUBJECTS AT AIISH

AIISH Institute Review Board (IRB)

Ref: SH/IRB/M.5/SLP.10/2025-26 **Date: 11.03.2026**

Title of the Dissertation	: Validation of the Feeding Swallowing Impairment Survey- Kannada (FS-IS-K) on Children with Feeding Difficulties Secondary to Neurodevelopmental Disorders
Name of the Student	: Ms. D Hithyshree
Guide	: Dr. Swapna N
Co-Guide (if any)	: NIL
Proposed Duration of the Project	: 06 months
Source of funding	: Non-funded Master's dissertation
Estimated budget	: Nil
Reference Number of the Project	: Nil
Date on which the IRB meeting was held	: 05.03.2026

A clear statement of the decision reached IRB meeting
(In the event of the proposal is not approved,
a statement of reasons for the same must be indicated) : **APPROVED**

Advice & suggestions (if any) : A permission letter from the respective special schools must be provided.

Signature & Name of the Member Secretary-IRB
Dr. Animesh Barman
Professor of Audiology
All India Institute of Speech and Hearing, Mysore-570006

Member Secretary
Institutional Review Board
अखिल भारतीय वाक् श्रवण संस्थान
All India Institute of Speech and Hearing
मानसगंगोत्री / Manasagangothri
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Appendix 2

Consent form for participation

ಅನುಬಂಧ – 5

ತಿಳಿದ ಒಪ್ಪಿಗೆ ಪತ್ರ

ಈ ಅಧ್ಯಯನದ ಪ್ರಕ್ರಿಯೆಗಳ ಕುರಿತು ನನಗೆ ಸಮರ್ಪಕ ಮಾಹಿತಿ ನೀಡಲಾಗಿದೆ. ಮಾನವ ವಿಷಯವಾಗಿ ಈ ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸುವುದರಿಂದ ಉಂಟಾಗುವ ಸಾಧ್ಯ ಅಪಾಯಗಳು ಮತ್ತು ಪ್ರಯೋಜನಗಳ ಕುರಿತು ನನಗೆ ಸ್ಪಷ್ಟವಾಗಿ ತಿಳಿದಿದೆ.ನಾನು ಯಾವಾಗ ಬೇಕಾದರೂ ಈ ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸುವುದನ್ನು ನಿರಾಕರಿಸುವ ಅಥವಾ ಹಿಂತೆಗೆದುಕೊಳ್ಳುವ ಹಕ್ಕು ಹೊಂದಿದ್ದೇನೆ ಎಂಬುದನ್ನು ಅರ್ಥಮಾಡಿಕೊಂಡಿದ್ದೇನೆ. ತನಿಖಾ ತಂಡವು ನಡೆಸುವ ಮೌಲ್ಯಮಾಪನಗಳಿಗೆ ನಾನು ಹೆಚ್ಚುವರಿ ಸಮಯ ಮೀಸಲಿಡಬೇಕಾಗುತ್ತದೆ ಮತ್ತು ಈ ಮೌಲ್ಯಮಾಪನಗಳು ನನಗೆ ನೇರ ಪ್ರಯೋಜನ ನೀಡುವುದಿಲ್ಲ ಎಂಬುದನ್ನು ನನಗೆ ತಿಳಿದಿದೆ. ಈ ನಿಯಮಾವಳಿಗಳಲ್ಲಿ ಯಾವುದೇ ಉಲ್ಲಂಘನೆ ನಡೆದರೆ, ಈ ಸಂಸ್ಥೆಯಿಂದ ನನಗೆ ದೊರೆಯುವ ವೈದ್ಯಕೀಯ ಸೇವೆಗಳನ್ನು ನಿರಾಕರಿಸುವ ಅಪಾಯವಿಲ್ಲದೆ, ನಾನು ಮಾನವ ಪ್ರಯೋಗ ಸಮಿತಿಯ ಅಧ್ಯಕ್ಷರಿಗೆ (Chairman, AEC) ಬರೆಯುವ ಸ್ವಾತಂತ್ರ್ಯ ಹೊಂದಿದ್ದೇನೆ.

ನಾನು, _____ (ಹೆಸರು), ಈ ಅಧ್ಯಯನ/ಪರೀಕ್ಷೆ/ಕಾರ್ಯಕ್ರಮದಲ್ಲಿ ಭಾಗವಹಿಸಲು ನನ್ನ ಒಪ್ಪಿಗೆ ನೀಡುತ್ತಿದ್ದೇನೆ.

ಭಾಗವಹಿಸುವವರು/ಪೋಷಕರ ಹೆಸರು ಮತ್ತು ಸಹಿ:

ದಿನಾಂಕ: _____

ಸಂಶೋಧಕರ (ವಿದ್ಯಾರ್ಥಿನಿ) ಹೆಸರು ಮತ್ತು ಸಹಿ:

ದಿನಾಂಕ: _____

Letter for seeking permission from Special Schools

ALL INDIA INSTITUTE OF SPEECH AND HEARING: MYSORE-6

To,
Devaiah
Devdan Foundation, Mysore

Subject: Request for participants for the dissertation research

Respected Ma'am/Sir,
I, Ms D. Hithyshree, a 2nd M.Sc. (SLP) student at All India Institute of Speech and Hearing, Mysore, am conducting a dissertation study titled "Validation of the Feeding/Swallowing Impairment Survey – Kannada (FS-IS-K) on Children with Feeding Difficulties Secondary to Neurodevelopmental Disorders." This study is carried out under the guidance of Dr. Swapna N., Professor of Speech Pathology and Coordinator, Centre for Swallowing Disorders, AIISH, Mysuru.
For the purpose of the study, I need to administer certain questionnaires to parents of children who experience feeding difficulties associated with conditions such as ASD, ID, and ADHD. Feeding difficulties will first be ascertained through a brief screening checklist before proceeding with the questionnaires.
The entire data collection process for each participant will take approximately 30 to 40 minutes. All information collected will be used strictly for academic purposes and will be kept confidential. Participation will be voluntary, and informed consent will be obtained prior to the administration of the screening checklist and questionnaires.
Additionally, appropriate guidance and suggestions regarding feeding difficulties will be provided to the parents after the assessment.
I kindly request your permission to carry out this study in your institution. I assure you that the research will be conducted ethically and without causing any inconvenience to the participants or the institution.
Thank you.
Yours sincerely,

Ms. D. Hithyshree
2nd Year M.Sc. (SLP)
AIISH, Mysuru

Guide: Dr. Swapna N.
Head of Department – Clinical Services
Professor of Speech Pathology & Coordinator,
Centre for Swallowing Disorders, AIISH, Mysuru

डॉ. स्वप्ना एन. / Dr. Swapna N.
आई.एस.एल.पी.एच. के प्राध्यापक
Professor of Speech Pathology &
विगलने संबंधि विकारों के लिए केंद्र के समन्वयक
Coordinator-Centre for Swallowing Disorders
अखिल भारतीय वाक् श्रवण संस्थान
All India Institute of Speech and Hearing
मानसगंगोत्री / Manasagangothri,
मैसूरु / MYSURU-570 006

DEVDAN FOUNDATION
CHARITABLE TRUST
1, Trust for Human and Community
Development (THCD) Convent Road,
Lashkar Mohalla, MYSORE

ALL INDIA INSTITUTE OF SPEECH AND HEARING: MYSORE-6

To,

Sahara School

Subject: Request for participants for the dissertation research

Respected Ma'am/Sir,

I, Ms D. Hithyshree, a 2nd M.Sc. (SLP) student at All India Institute of Speech and Hearing, Mysore, am conducting a dissertation study titled "Validation of the Feeding/Swallowing Impairment Survey – Kannada (FS-IS-K) on Children with Feeding Difficulties Secondary to Neurodevelopmental Disorders." This study is carried out under the guidance of Dr. Swapna N., Professor of Speech Pathology and Coordinator, Centre for Swallowing Disorders, AIISH, Mysuru.

For the purpose of the study, I need to administer certain questionnaires to parents of children who experience feeding difficulties associated with conditions such as ASD, ID, and ADHD. Feeding difficulties will first be ascertained through a brief screening checklist before proceeding with the questionnaires.

The entire data collection process for each participant will take approximately 30 to 40 minutes. All information collected will be used strictly for academic purposes and will be kept confidential. Participation will be voluntary, and informed consent will be obtained prior to the administration of the screening checklist and questionnaires.

Additionally, appropriate guidance and suggestions regarding feeding difficulties will be provided to the parents after the assessment.

I kindly request your permission to carry out this study in your institution. I assure you that the research will be conducted ethically and without causing any inconvenience to the participants or the institution.

Thank you.

Yours sincerely,

Ms. D. Hithyshree
2nd Year M.Sc. (SLP)
AIISH, Mysuru

Swapna

Guide: Dr. Swapna N.
Head of Department, Clinical Services
Professor of Speech Pathology & Coordinator,
Centre for Swallowing Disorders, AIISH, Mysuru

डॉ. स्वपना एन. / Dr. Swapna. N
Professor of Speech Pathology & Audiology
विशेषज्ञ वाक् विकृति व श्रवण विज्ञान के प्राध्यापक
Coordinator-Centre for Swallowing Disorders
अखिल भारतीय वाक् श्रवण संस्थान
All India Institute of Speech and Hearing
मानसगंगोत्री / Manasagangothri,
मैसूरु / MYSURU-570 006

SAHARA SCHOOL FOR CHILDREN WITH SPECIAL NEEDS
200, 2nd Cross, 2nd Stage
Tippu Park, Udayagiri
MYSURU-570 019

Appendix 3

Feeding/Swallowing Impact Survey-Kannada

ಮಕ್ಕಳಿಗೆ ಆಹಾರ ಉಣಿಸುವಿಕೆ/ ನುಂಗುವಿಕೆಯ ತೊಂದರೆಗಳು ಪೋಷಕರ ಮೇಲೆ ಉಂಟುಮಾಡುವ ಪರಿಣಾಮಗಳ ಸಮೀಕ್ಷೆ

	ನಿಮ್ಮ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆ/ ನುಂಗುವಿಕೆಯಲ್ಲಿನ ತೊಂದರೆಯಿಂದಾಗಿ ಕಳೆದ ಒಂದು ತಿಂಗಳಲ್ಲಿ ಮಗುವಿಗೆ ಆಹಾರ ತಿನ್ನಿಸುವುದು ಎಷ್ಟು ಕಷ್ಟವಾಗಿದೆ?	ಎಂದಿಗೂ ಇಲ್ಲ	ಬಹುತೇಕ ಎಂದಿಗೂ ಇಲ್ಲ	ಅರ್ಧಕ್ಕಿಂತ ಹೆಚ್ಚು ಸಮಯ	ಆಗಾಗ	ಬಹುತೇಕ ಯಾವಾಗಲೂ	ಅನ್ವಯಿಸುವುದಿಲ್ಲ
1.	ಮಗುವಿನ ನುಂಗುವ ಸಾಮರ್ಥ್ಯಕ್ಕೆ ತಕ್ಕಂತೆ ದ್ರವಾಹಾರ ಮತ್ತು ಇತರ ಆಹಾರವನ್ನು ತಯಾರಿಸಲು ಹೆಚ್ಚು ಸಮಯ ತೆಗೆದುಕೊಳ್ಳುವುದರಿಂದ ಮಗುವಿಗೆ ಸರಿಯಾಗಿ ತಿನ್ನಿಸಲು ಆಗುತ್ತಿಲ್ಲ.	1	2	3	4	5	6
2.	ಮಗುವಿಗೆ ಅಗತ್ಯವಾಗಿರುವ ದ್ರವಪದಾರ್ಥ ಹಾಗೂ ಇತರೆ ಆಹಾರವನ್ನು ತಯಾರಿಸಲು ನನಗೆ ತಿಳಿದಿಲ್ಲದಿರುವುದರಿಂದ ಮಗುವಿಗೆ ಆಹಾರ ನೀಡುವುದು ಕಷ್ಟವಾಗಿದೆ	1	2	3	4	5	6
3.	ಇತರರು ನನ್ನ ಮಗುವಿಗೆ ಸೂಕ್ತವಲ್ಲದ ದ್ರವಪದಾರ್ಥ ಹಾಗೂ ಇತರೆ ಆಹಾರವನ್ನು ನೀಡುವುದರಿಂದ ಮಗುವಿಗೆ ಆಹಾರ ತಿನ್ನಿಸುವುದು ಕಷ್ಟವಾಗಿದೆ	1	2	3	4	5	6
4.	ನನ್ನ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆ/ ನುಂಗುವಿಕೆಯ ಸಮಸ್ಯೆಗಳು ಎಲ್ಲಿಯವರೆಗೆ ಇರುತ್ತವೆ ಎಂಬುದು ತಿಳಿದಿಲ್ಲವಾದ್ದರಿಂದ ಆಹಾರ ತಿನ್ನಿಸುವುದು ಕಷ್ಟವಾಗಿದೆ	1	2	3	4	5	6
5.	ಮಗುವಿಗೆ ಆಹಾರ ಉಣಿಸುವ ತೊಂದರೆಗಳ ಬಗ್ಗೆ ಮನೆಯವರು ಮತ್ತು ವೃತ್ತಿಪರರ ವಿಭಿನ್ನ ಅಭಿಪ್ರಾಯ/ ಸಲಹೆಗಳು ನೀಡಿರುವುದರಿಂದ ಮಗುವಿಗೆ ಆಹಾರ ತಿನ್ನಿಸಲು ಕಷ್ಟವಾಗಿದೆ.	1	2	3	4	5	6
6.	ಇತರ ಮಕ್ಕಳಂತೆ ನನ್ನ ಮಗುವು ಸಹ ಆಹಾರ ಸೇವಿಸುವಂತೆ ಮಾಡುವ ಬಗ್ಗೆ ನನಗೆ ಸರಿಯಾದ ಮಾಹಿತಿ ಇಲ್ಲದ ಕಾರಣ ಮಗುವಿಗೆ ಆಹಾರ ತಿನ್ನಿಸುವುದು ಕಷ್ಟ	1	2	3	4	5	6

ನಿಮ್ಮ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆ/ ನುಂಗುವಿಕೆಯಲ್ಲಿನ ತೊಂದರೆಯ ಕಾರಣದಿಂದಾಗಿ ಕಳೆದ ಒಂದು ತಿಂಗಳಲ್ಲಿ ದಿನನಿತ್ಯದ ಕೆಲಸಗಳಲ್ಲಿ ಕಂಡು ಬಂದಿರುವ ತೊಂದರೆಗಳು		ಎಂದಿಗೂ ಇಲ್ಲ	ಬಹುತೇಕ ಎಂದಿಗೂ ಇಲ್ಲ	ಅರ್ಧಕ್ಕಿಂತ ಹೆಚ್ಚು ಸಮಯ	ಆಗಾಗ	ಬಹುತೇಕ ಯಾವಾಗಲೂ	ಅನ್ವಯಿಸುವುದಿಲ್ಲ
1.	ನನ್ನ ದಿನನಿತ್ಯದ ಕೆಲಸ-ಕಾರ್ಯಗಳು, ಶಾಲೆಗೆ ಹೋಗುವುದು ಹಾಗೂ ಮನೆಕೆಲಸಗಳನ್ನು ಮಾಡಲು ಕಷ್ಟವಾಗಿದೆ	1	2	3	4	5	6
2.	ಇತರರು ನನ್ನ ಮಗುವಿಗೆ ಆಹಾರ ತಿನ್ನಿಸಲು ಹಾಗೂ ನೋಡಿಕೊಳ್ಳಲು ಹೆದರುವುದರಿಂದ ಈ ವಿಚಾರದಲ್ಲಿ ಅವರ ಸಹಾಯ ಪಡೆಯುವುದು ಕಷ್ಟವಾಗಿದೆ	1	2	3	4	5	6
3.	ನನಗೆ ಮಗುವನ್ನು ಬೇರೆಯವರೊಂದಿಗೆ ಬಿಟ್ಟು ಹೋಗಲು ಹಿಂಜರಿಕೆಯಿದೆ. ಏಕೆಂದರೆ, ಇತರರು ನನ್ನ ಮಗುವನ್ನು ನೋಡಿಕೊಳ್ಳುವ ಹಾಗೂ ಆಹಾರ ತಿನ್ನಿಸುವ ವಿಚಾರದಲ್ಲಿ ನನಗೆ ಆತಂಕವಿದೆ.	1	2	3	4	5	6
4.	ನನ್ನ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆಯಲ್ಲಿ ತೊಂದರೆಯಿಂದ ನನ್ನ ಕುಟುಂಬದೊಂದಿಗೆ ಹೊರಗಡೆ ಹೋಗಲು ಹಾಗೂ ಹೊರಗಡೆ ಊಟ ಮಾಡಲು ಕಷ್ಟ	1	2	3	4	5	6
5.	ನನ್ನ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆಯ ತೊಂದರೆಯಿಂದಾಗಿ ನನ್ನ ಅಗತ್ಯ ಕೆಲಸಗಳು ಅಥವಾ ಮಾಡಬೇಕಾಗಿರುವ ಕೆಲಸಗಳನ್ನು ಮಾಡಲು ತುಂಬಾ ಸುಸ್ತಾಗುತ್ತದೆ	1	2	3	4	5	6

ನಿಮ್ಮ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆ/ ನುಂಗುವಿಕೆಯಲ್ಲಿನ ತೊಂದರೆಯ ಬಗ್ಗೆ ಕಳೆದ ಒಂದು ತಿಂಗಳಲ್ಲಿ ಎಷ್ಟು ಬಾರಿ ಚಿಂತೆಗೆ ಒಳಗಾಗಿದ್ದೀರಿ?		ಎಂದಿಗೂ ಇಲ್ಲ	ಬಹುತೇಕ ಎಂದಿಗೂ ಇಲ್ಲ	ಅರ್ಧಕ್ಕಿಂತ ಹೆಚ್ಚು ಸಮಯ	ಆಗಾಗ	ಬಹುತೇಕ ಯಾವಾಗಲೂ	ಅನ್ವಯಿಸುವುದಿಲ್ಲ
1.	ನನ್ನ ಮಗುವಿನ ಆರೋಗ್ಯದ ಬಗ್ಗೆ ನನಗೆ ಯೋಚನೆಯಿದೆ	1	2	3	4	5	6
2.	ನನ್ನ ಮಗುವು ತನ್ನ ದೇಹಕ್ಕೆ ಅಗತ್ಯವಾದಷ್ಟು ಆಹಾರ ಸೇವಿಸುತ್ತಿಲ್ಲ ಅಥವಾ ಪಡೆಯುತ್ತಿಲ್ಲ ಎನ್ನುವ ಚಿಂತೆಯಿದೆ	1	2	3	4	5	6
3.	ನನ್ನ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆ/ ನುಂಗುವಿಕೆಯ ತೊಂದರೆಯ ಕುರಿತು ಇತರರು ಹೇಗೆ ಪ್ರತಿಕ್ರಿಯಿಸುತ್ತಾರೆ ಎನ್ನುವ ಚಿಂತೆಯಿದೆ	1	2	3	4	5	6
4.	ನನ್ನ ಮಗುವು ಆಹಾರ ಸೇವಿಸುವಾಗ ಉಸಿರಾಟದ ಸಮಸ್ಯೆ ಉಂಟಾಗುವುದೇನೋ ಅಥವಾ ಉಸಿರುಗಟ್ಟುವುದೇನೋ ಎಂದು ಆತಂಕವುಂಟಾಗುತ್ತದೆ	1	2	3	4	5	6
5.	ನನ್ನ ಮಗುವು ಇತರ ಸಾಮಾನ್ಯ ಮಕ್ಕಳಂತೆ ಆಹಾರ ತಿನ್ನಲು/ನುಂಗಲು ಸಾಧ್ಯವಾಗುವುದೇ ಇಲ್ಲ ಎನ್ನುವ ಚಿಂತೆಯಿದೆ	1	2	3	4	5	6
6.	ನನ್ನ ಮಗುವು ಆಹಾರ ತಿನ್ನಲು/ ನುಂಗಲು ನಾನು ಸಾಧ್ಯವಾದಷ್ಟು ಸಹಾಯ ಮಾಡುತ್ತಿದ್ದೇನೆಯೇ ಅಥವಾ ಇಲ್ಲವೇ ಎಂಬ ಚಿಂತೆಯಿದೆ.	1	2	3	4	5	6
7.	ನನ್ನ ಮಗುವಿನ ಆಹಾರ ಸೇವನೆ/ನುಂಗುವ ಸಮಸ್ಯೆಯು ಕುಟುಂಬದ ಇತರರ ಮೇಲೆ ಪರಿಣಾಮ ಬೀರುತ್ತದೆ ಎಂಬ ಚಿಂತೆಯಿದೆ	1	2	3	4	5	6