TRANS-ADAPTATION AND VALIDATION OF FEEDING/ SWALLOW IMPAIRMENT SURVEY (FS-IS) SCREENING TOOL IN KANNADA

SHALABHA AMMU MATHEW

Register No: P01II22S123025

A Dissertation Submitted in Part Fulfilment of Degree of Master of Science (Speech-Language Pathology)

University of Mysore, Mysuru

ALL INDIA INSTITUTE OF SPEECH AND HEARING

MANASAGANGOTHRI, MYSURU- 570006

JULY, 2024

CERTIFICATE

This is to certify that this Dissertation entitled "**Trans-adaptation and Validation of Feeding/ Swallow Impairment Survey (Fs-Is) screening tool in Kannada**" is a bonafide work submitted in part fulfillment for the degree of Master of Science (Speech-Language Pathology) student with Registration Number P01II22S123025. 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.

Mysuru

July, 2024

Dr. M. Pushpavathi

Director

All India Institute of Speech and Hearing
Manasagangothri, Mysuru – 570006

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Mysuru

July, 2024

Dr. Swapna N

Guide

Professor of Speech Pathology

Center for Swallowing Disorders

All India Institute of Speech and Hearing

Manasagangothri, Mysuru- 570006

DECLARATION

This is to certify that this Dissertation entitled “**Trans-adaptation and Validation of Feeding/ Swallow Impairment Survey (FS-IS) screening tool in Kannada**” is a result of my study under the guidance of Dr. Swapna N, Professor of Speech Pathology, Centre for Swallowing Disorders and Head of Department of Department of Clinical Services, 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	Registration No.
July, 2024	P01II22S123025

Dedicated to Acha and Amma

(When I count my blessings, I count you both twice)

Acknowledgement

A big thank you to **God almighty** for your blessings in my life.

My sincere gratitude to my guide, **Dr. Swapna**, for accepting me as your dissertation student in the middle of an unforeseen situation. I am forever grateful to you for that, and thank you for your words, "I trust your skills." Honestly, this kept me moving. Thank you for showing me this journey of research. Looking forward for more opportunities with you.

Acha, thank you for trusting me and allowing me to make my own life decisions, including my career choices. Your 'Shalabha kunju' is soon to be a postgraduate. I am deeply grateful for the wonderful environment you provided for us, even better than what you had during your childhood. I would go to any extent to make you proud. Your vachakam on “Padikkan vitta padikkanam…………..”will be with us for a life time.

Amma, for all the sacrifices you have made for us and the tremendous efforts you have put into raising me and Eldho.Your dedication to involve us in extracurricular activities is something I truly appreciate. I still remember how you would be there when our school bell rang, carrying our heavy skating shoes and snacks. You tirelessly sought out dance, music, swimming, and badminton classes in every city we lived in. I greatly admire the multitasking woman in you. Like how I always say “THANKYOU for giving this BUTTERFLY a PRETTY life.

Eldho-From you getting tired of hearing “Shalabhede aniyan alle” to me now hearing “Vakeelinte aniyathi aano?” you have come a long way to become that good ‘Menon Payyan”. I can't wait to see you become Adv. Eldho Jacob Mathew and, in the long run, welcome the vakeel ammachi to our house.

Appachai, it has been 10 years since you left us. If you were here today, I know you would be so proud and eager to read my entire dissertation, just as you once took the time to read my projects and answer sheets.

Appachan and Ammachi-Thank you for being our best source of entertainment. Appachan, with your ‘chori varthanam’ and talented Ammachi adding her special touch with her extra ability to talk, you both make a perfect pair. I love you both. Ammachi I love listening to your voice notes

Heartfelt appreciation to **Dr. Jayashree C. Shanbal**. You will always hold a special place in my life. Thank you for supporting me during the toughest time of my postgraduation. Your strength and courage helped me take a stand for myself.

Freddy sir and Simran Ma’am for helping us get through our overthinking thoughts.Thankyou for letting us know the right thing at the right time. Like how you said “None of these things will bother you in the long run”.

Rectnamma ma’am, my primary school English teacher at Kendriya Vidyalaya Ernakulam, you were the first person to select me for anchoring back in 2009 when I was 10 years old. Ever since then, anchoring has been the one extracurricular activity I have consistently pursued for the past 15 years, and I love it. Even today, when I stand on stage and receive compliments, I always think of you. Though you are no longer in this world, I want you to know that I am deeply grateful to you for identifying this talent in me.

An amazing person I met during internship **Mr Prasanna Hegde**. A big thankyou to you and the wonderful “Team SLP Quest”. You and your WOW talks have always motivated me. Rachana Ma’am you have my heart, thankyou for simply existing. This rabbit loves you a lot.

Mahima and Drishti – Let's give ourselves a huge round of applause for everything we went through. We did it! Let's appreciate the wonderful conclusion to our dissertation journey. I feel incredibly fortunate to have found you both in my life. If given another chance, I’d choose you both again

Mahima: I admire you for the wonderful person you are. Time has flown by from the day you made that salty omelette to seeing you wake up early for NSS events just because I was the leader. In you, I've found a best friend forever. You've spoiled me (hehehe), but you're someone I wouldn't want to be without. Here's to more of your genuine, bold advice. 'Tum jaisi ho waisi hi raho.' You are always MY GREEN.

Drishti: Enta Cheyya with all this love? Sometimes miracles come to us in the form of good people, and with you, it started even before we met. Thank you for all the love you keep showering on me. From laughing out loud in serious situations and struggling to stand face to face during NSS assemblies (because we might burst out laughing), to trying our best to get serious for exams, I've found a forever friend in you. You'll always be close to my heart. 'Na Jaane kyun Tu hai toh I’ll be alright!'

Havya-An investment since 6 years and counting. If not with you with whom will I have those intellectual conversations. A pat on the back for all the hurdles we faced. Cheers for the good times we have had. I Love us .To more of hearing “Ammu nee evedeya” from you

Sruti- My masters wouldn’t have been complete without you. To more of talking and healing with you. I love the way we vibe.

Varna and Masha-Cheers for the good times we have spent. Masha hoping to see write more short stories.

Jyoti-My perfect pack of energy from Kuwait. Thankyou for those international calls. Kudos for not giving up despite the hurdles we faced. To more of seeing us grow

I will always cherish the night that celebrated **Nuha and friends (Aslin, Nuh, Neh, Percy, Krish, Anshu, Gowri, Maiju, Jillam ,Maji, Drishti and Mahima).** You guys are a lovely bunch of good souls. Thankyou for standing with me when I wanted support the most.

Harshada- To the long walks and food we have had together. I value the good soul in you

To my seniors **-Swalih sir** ,you genuinely played an important role throughout these 6 years in college. From sending notes to checking on me frequently for entrance exam as well as my dissertation process is something that I would forever be grateful.

Urvi di for all the help and suggetsions you did back in 1st Msc. **Sneha chechi** and **Kripa chechi** for always being my helping hand

My lovely juniors : **Riya, Nahan, Annly ,Ashwati, Aditya, Lakshmi and Aleena**. Thankyou for the good times spent together

Team Alamboos**- Meera, Rinsha, Jyoti, Sahana, Aneesha, Neethu, Ines, Suhada and Christa**. It was never easy for me and Havya to start masters without you all. For the happy bachelor time we had together. Hurrays for the bridal showers, vallagap and the Manglore conference that gave us the opportunities to meet in the last two years.To many more.

Moksh ji for the wonderful brain you have. **Ashish** for the vibe of a person you are,its always nice talking to you.**Muda** for the exceptional knowledge and courage you have gathered in the past years. I have a deep respect for you.**Sooraj** -we definitely missed you in our class. To more good times together.

Another circle of friendships made through friend's friend-**Myaloof Kasim, Ijaz and Sarang**. Your vibe hits different.

Lastly**, Dear me**- We've come a long way. This marks a beautiful end to your chapter on 'Masters in Speech Langauge Pathology'.

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Chapter I

Introduction

Feeding related issues have always been a serious concern in pediatric population. About 10% of paediatric population experience feeding disorders, requiring access to the extensive caregiving and health care system (Raina et al., 2004), often throughout childhood and into the adult years. Airway malformations, cerebral palsy, intellectual disability, autism spectrum disorder, traumatic brain injury, neuromuscular disorders, craniofacial malformations, cardiac diseases, ingestional injuries, gastrointestinal diseases are some of the etiologies for feeding and swallowing difficulties. Eighty percent of children with developmental disabilities and complex medical conditions were found to have at least one feeding deficit (Dharmaraj et al., 2023).

The common signs and symptoms of feeding and swallowing difficulties include uncoordinated sucking, immature biting and chewing, poor bolus propulsion, primitive or weak oral reflexes, absent swallow reflex, delayed triggering of swallow, penetration of food into laryngeal vestibule, nasopharyngeal regurgitation etc. (Dodrill & Gosa, 2015). This impacts children negatively with reduced desire to eat, disruption in meal time, undernutrition, constipation, growth failure, aspiration risks, frequent hospitalization due to aspiration pneumonia etc. (Andrew & Sullivan, 2010a; Sullivan et al., 2000, 2004a). Such difficulties that persist over a long time, would require caregivers to give extra care routines to their child, which could be physically and emotionally taxing to the carers (Goday et al., 2019; Silverman et al., 2021a).

Studies report that based on nutritional requirements, caregivers adopt feeding strategies such as positioning, diet modification, appropriate utensil usage and pacing techniques (Harding & Cockerill, 2014). However, carers report difficulty in carrying out these preparatory strategies before mealtime and to monitor, prompt and observe the child during mealtime. Monitoring includes checking if the food particles are properly chewed before the child swallows and also to look out for food debris in the oral cavity post swallow. Prompting the child would include providing different types of prompts to the child, so as to ensure that they eat the food served. Positioning the children in special furniture during feeding every meal becomes crucial, especially for those with motor issues. For some children, diet modification may be recommended, which means that the caregivers have to prepare food in a particular consistency for their children during each mealtime, which might increase the overall burden. Some children refuse to drink water and eat food, which leads to nutritional problems, which inturn increases stress among caregivers (Charpentier et al., 2020; Sullivan et al., 2000). As a result, carer-child dyad communication levels become more directive, rather than the typical interactive communication style, with the carer taking up a controlling role (Harding et al., 2013; Veness & Reilly, 2008). Helplessness of the parent to provide physical nourishment to their child affects their confidence and self-esteem in parenting resulting in extreme frustration (Greer et al., 2008). Hence, there is clear evidence of caregiver's life being affected, which includes sleep disturbance, reduced work capacities and financial difficulties.

A study by Raina et al. (2004) describes a process called "Caregiver Career", wherein a caregiver proceeds through various stages, such as preparing for taking up the caregiver role, enacting the associated tasks and responsibilities and disengaging from other responsibilities. This whole process requires rearrangement of priorities and redirection of energy. Lack of proper support and services during the management of dysphagia will affect the wellbeing and quality of life of the primary caregiver (Li et al., 2014). Parents state heightened levels of stress and anxiety with an overall reduction in confidence, which again impacts their parenthood(Powers et al.,2002). Additional work for parents such as preparing alternative meal or making it to the consistency preferred by the child, having proactive plans when the child refuses to have food and to deal with food aversion are all factors that contribute to stress (Powers et al.,2002).

Higher levels stress and worthless feeling are also reported in parents of children who exhibit aggressive behaviours only during mealtime interaction, than of parents whose children are diagnosed with feeding disorder due to a medical or a developmental etiology (Silverman et al., 2021). Mealtime aggressive behaviours such as food refusal and aversion and externalizing behaviours such as aggressiveness are significant indicators of caregiver stress whereas, internalizing behaviours such as anxiety or mood of the child indicates dysfunctional interactions (Silverman et al., 2021).Thus, higher the caregiver stress is, lower the parental efficacy in implementing the dysphagia management strategies during every mealtime (Crist et al., 1994). Maternal depression was positively related to the mother's perception of how difficult the child is to be taken care of (Davis et al., 2003; Silver et al., 1998). Previous studies report that the severity and duration of child's impairment has a positive correlation with caregiver stress (Carson & Schauer, 1992; Humphry & Rourk, 1991; Quittner et al., 1992).

A study by Arslan et al. in 2020 involved caregivers of 64 children with esophageal atresia and tracheoesophageal fistula (EA-TEF). All primary caregivers were mothers, with an average age of about 31 years. The caregivers' experiences were evaluated using the Turkish Feeding/Swallowing Impact Survey (T-FS-IS) (Serel Arslan et al., 2018), which assessed daily activities, worry, feeding difficulties, and provided an overall score. Results showed that caregivers of children with isolated EA expressed more concerns in all areas compared to those with children who had EA with distal TEF. Caregivers whose children had delayed surgical repair reported greater difficulties across all areas compared to those whose children received early repair. There was a moderate to strong correlation between the total T-FS-IS score and the time to start oral feeding, indicating that earlier initiation of feeding is linked to fewer concerns. The key findings revealed that caregivers' concerns regarding feeding and swallowing difficulties are strongly related to the children's medical history, particularly the type of atresia and the timing of surgical repair. Delayed repair and isolated EA were linked to higher levels of concern among caregivers. This study emphasizes the significance of prompt medical interventions and support to reduce these concerns.

A delay in the oral intake may also hinder the development of swallowing experience as the feeding abilities are usually achieved in the first two years of life. Caregiver burden is more when children have other comorbidities and delay in medical treatment or intervention, which causes additional burden on the caregivers.

Another study was done on 164 caregivers of children with cerebral palsy, presenting for the first time with a complaint of feeding/swallowing difficulties. Caregiver difficulties were assessed using an 18-item questionnaire called Feeding/Swallowing Impact Survey (FS-IS) (Lefton-Greif et al., 2014; Serel Arslan et al., 2018). This study addresses a significant gap in the literature, as caregivers of medically complex children often experience substantial physical and emotional challenges that impact their well-being. The study aimed to identify and track the specific needs of these caregivers, providing crucial information for health care providers who increasingly rely on caregivers for better health outcomes of these children. Caregivers faced significant challenges, including time, economic pressures, and worries about choking or nutritional intake with higher concerns in the form of aspiratory risks and failure to thrive, in children who had severe impairments in swallowing. Approximately half of the children in the study were under 12 months old, and this inturn highlights the intense demands on caregivers of younger children. Need for health care providers to support caregivers by setting realistic expectations and providing family-centered multidisciplinary care to improve caregiver's quality of life is emphasized in the study.

A study was done on 35 caregivers of children with aspiration due to known laryngeal cleft diagnosed by suspension laryngoscopy and inspection (Fracchia et al., 2017). The primary objective of the study was to cross validate FS-IS scale and measure quality of life on these caregivers. Aspiration was diagnosed through clinical history and videofluoroscopic swallow studies (VFSS). The caregivers were divided into three groups: the first group had children with a diagnosed but unrepaired laryngeal cleft, the second group had children 6-12 months post-repair with significant improvement in VFSS and reduced clinical symptoms, and the third group had children 6-12 months post-repair with little to no improvement in VFSS, diet, or symptoms. All children had an initial VFSS, and those who underwent repair also had a postoperative VFSS. Caregivers answered 18 questions on their quality of life before and after the cleft repair, covering the impact on daily activities, time spent worrying about their child, and difficulties feeding the child. There was a significant correlation between the average postoperative FS-IS scores and the VFSS, with responders on VFSS scoring significantly lower than non-responders, demonstrating convergent validity. Discriminant validity was shown by comparing the average FS-IS scores of caregivers of children, who had not undergone cleft repair with those of caregivers of children who showed improvement after repair. The average FS-IS score was significantly lower in caregivers of children who responded to treatment, indicating that the instrument can distinguish between different subpopulations as hypothesized. They reported that parents of children who underwent cleft repair had better quality of life, as the feeding difficulties reduced with treatment. Secondly, parents of children who had improvement in swallow, post cleft repair had higher satisfaction that those who did not show improvement

Mothers of children with severe impairments showed poorer physical and mental health, received less emotional support from family and friends and had higher demands placed on their time and finances (Leonard et al., 1993). Fifty-three percent of caregivers reported that caregiving duties took away their family and friends, 89.2 % had less leisure time, and 23 % reported that caregiving resulted in financial hardship (Cohen et al., 2015; Gibson & Houser, 2007; López et al., 2005).

Need for the Study

Caregiver quality of life associated with feeding disorders in children is a neglected area and is highly under researched. Not much work has been done specifically to assess the quality of life of caregivers of children with feeding difficulties. A look into the existing literature revealed that paediatric feeding disorders have an immense impact on caregivers. Early identification of dysphagia-specific caregiver QOL and the commencement of early intervention can improve the health outcomes and better quality of life of the caregivers and their care recipients.

To the best of our knowledge, there exists only one scale to assess feeding specific caregiver quality of life applicable for paediatric population, which is Feeding/Swallowing Impact Survey (FS-IS, Lefton-Greif et al., 2014). Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) tool (Daniella et al., 2022; Namasivayam-MacDonald & Shune, 2018) is available, however, this is for screening caregiver burden in the adult population with dysphagia. FS-IS is an inventory (an 18-item tool) to recognize and enhance comprehension of caregiver problems associated with caring for children with feeding/swallowing disorders. It covers problems carrying out daily activities, problems with worrying and problems feeding the child. This was developed to measure the impact of feeding/swallowing problems on caregiver health related quality of life. The three subscales in FS-IS include Daily Activities, Worry, Feeding Difficulties. It employs a 5- point Likert scale ranging from a score of "1" indicating never to a score of "5" indicating almost always. Higher scores indicate poorer caregiver quality of life**.** Principal Component Analysis (PCA) with promax rotation identified three factors corresponding to the subscales of daily activities, worry, and feeding difficulties. The internal consistency of these subscales was confirmed with high Cronbach alphas (total score = 0.89), indicating the reliability of the results surveyed in 164 children. The scale was validated by comparing it with the PEDS-QL™ Family Impact Module (FIM) (Davis et al., 2010), which obtained significant correlation. The scale also effectively distinguished between caregivers of children with severe feeding/swallowing issues (e.g., those needing feeding tubes) and those without such severe issues, showing its ability to detect variations in caregiver impact. FS-IS was able to detect greater interference in daily activities for caregivers of children with more severe conditions, like those requiring feeding tubes. This indicates that the tool is sensitive to variations in the severity of children's conditions and their impact on caregivers. FS-IS did not show significant differences between few demographic groups such as white and non-white families, above and below median household income etc. suggests that the tool may have good specificity in not falsely identifying unaffected caregivers as impacted

The existing literature indicates higher prevalence of feeding/swallow related impairments in India (Pavithran et al., 2020). Considering the increasing population of individuals with feeding and swallowing difficulties in India, there is a need for a similar tool in the Indian context. Acknowledging the differences in family system (nuclear/joint), population type (urban/rural), linguistic diversity, family conduct, culture, food habits and diverse educational and socioeconomic status of India compared to other countries, it is essential to validate the FS-IS, in the Indian population, thus, necessitating a need for replication.

Presently no standardized tool exists to evaluate and measure the feeding/swallow-related caregiver burden in any Indian language, including Kannada. The original FS-IS screening tool is developed and validated in English; hence, specific terms/phrases in the questionnaire may be complex for India's general population to understand. Further, there may be other additional contributors or aspects of caregiver burden relevant to the Indian context. This necessitates the need for the instrument to be adapted, translated and validated in Indian languages.

FS-IS has been identified as a potent tool to identify quality of life (QOL) for caregivers of children with feeding and swallowing disorders. FS-IS was found to be an appropriate tool to assess parental concerns regarding aspiratory risks in children with cerebral palsy (Lefton-Greif et al., 2014; Serel Arslan et al., 2018; Serel Arslan et al., 2020). FS-IS is available in English(Lefton-Greif et al., 2014) and has been translated and validated to various languages such as Brazilian Portuguese (Rama et al., 2022), Turkish (Serel Arslan et al., 2018), South African (Bestenbier et al., 2021) and Persian (Mokhlesin et al., 2023). Adapting and translating the FS-IS, would help researchers and clinicians in India to document the burden of caregiving experienced by the caregivers of children with feeding/ swallow impairment. It would also allow better clinical decision-making and facilitate the development of comprehensive and effective dysphagia management plans. Keeping this in view, the present study was planned.

Aim of the study

The present study aimed to trans-adapt the FS-IS screening tool in Kannada and validate the tool on caregivers of children with feeding or swallow impairments secondary to cerebral palsy.

Objectives of the study

1. To adapt and translate the caregiver burden screening tool FS-IS in Kannada.
2. To validate the tool for its contents
3. To administer the tool on caregivers of children with cerebral palsy as a part of its clinical validation.
4. To determine the concurrent validity
5. To determine the test-retest reliability of the tool.
6. To determine the relation between caregiver variables such as age, socioeconomic status, education, and care-recipient variables such as age, gender, age of identification of feeding deficits, dependency status with feeding specific caregiver quality of life.

Null Hypothesis

H_{01}- There is no association between feeding specific caregiver quality of life and the general caregiver burden scores as measured using the Kannada version of 'The Burden of Persons with Aphasia on the caregivers'.

H_{02}- There is no association between feeding specific caregiver quality of life and severity of feeding and swallowing issues established using the Feeding Handicap Index tool.

H_{03}-There is no association between caregiver age, education, socioeconomic status, care-recipient age, gender, age of identification of feeding deficits, dependency status and feeding specific caregiver quality of life.

Chapter II

Review of Literature

The development of feeding and swallowing skills is a gradual process that begins before birth. It involves several stages, reflecting both physiological and motor development. Feeding starts with suckling reflex for drawing milk into the mouth, followed by coordinated suck/swallow/breathe pattern, which emerges around 37 weeks post-conceptional age(Ross & Browne, 2002). As infants grow, they begin to lose the suckling reflex (usually around 6 months) and start eating solid foods, which require different oral movements compared to suckling. They then acquire the ability to take food from spoon with lips closed by 6 to 9 months. The infants learn to use the tongue to push food against the hard palate, helping to mash and prepare the food for swallowing by 9-12 months. This action is crucial for transitioning from pureed to more textured foods. Between 12-18 months, they develop the ability to chew, involving up-and-down as well as side-to-side movements of the jaw. They start to feed themselves, initially with their hands by 9-15 months. This stage is important for developing fine motor skills and hand-eye coordination. Self-feeding is a critical step for gaining independence in eating. Around the same time, finger feeding also develops. By 15-24 months, they are more independent in self-feeding and start to learn basic table manners and how to behave during meals. These stages represent a gradual progression from reflex-driven feeding to complex, coordinated self-feeding behaviors, highlighting the intricate development of motor and sensory skills in children (Ayano et al., 2000).

Feeding plays a crucial role in a child's growth, learning, and establishment of relationships with others. It is closely linked to the development of social and communication skills (Rezaei et al., 2011). Feeding and swallowing are intricate processes involving the coordination of various physiological systems such as the central and peripheral nervous systems, oropharyngeal mechanism, cardiopulmonary system, and gastrointestinal tract. Any impairment in the structure or function of any of the systems related to feeding can result in challenges when performing activities like chewing, swallowing, and drinking (Case-Smith, 1989). The specific feeding difficulties include uncoordinated sucking, poor suck-swallow-breath coordination, immature biting, anterior spillage, poor bolus propulsion, food pocketing, primitive or weak oral reflexes, absent swallow reflex, delayed triggering of swallow, penetration of food into laryngeal vestibule, aspiration, nasopharyngeal regurgitation etc. (Dodrill & Gosa, 2015).

When feeding difficulties result in significant weight loss, inadequate growth, or developmental delays, they may be classified as feeding disorders (Estrem et al., 2018; Northstone et al., 2001). Recently, a proposal has introduced the term "paediatric feeding disorder" (PFD) to define impaired oral intake that does not match the child's age and is associated with medical, nutritional, feeding skill, and/or psychosocial issues (Elliot et al., 2024).This definition provides much-needed clarity, since the causes of PFDs can vary widely in severity and complexity (Elliot et al., 2024). Contributing factors to feeding difficulties may include premature birth, chronic illnesses, neurodevelopmental disorders, cancer, and disruptions in the caregiver-child relationship due to mental health issues or social challenges.

Etiologies of Feeding disorders

According to a study by Burklow et al. (1998), the etiologies of feeding are classified into various categories as described below:

(A) Structural abnormalities, such as retrognathic jaw, cleft palate, posterior tongue placement associated with Pierre–Robin syndrome and other conditions like macroglossia, tracheostomy, esophageal strictures, or stenosis etc. are identified as one of the causes that lead to feeding problems. For example, infants with cleft palate often struggle to create the negative pressure necessary for nipple feeding, because they cannot effectively seal the nasal cavity and nasopharynx from the oral cavity and oropharynx (Reid et al., 2007). This can cause nasopharyngeal regurgitation during feeding. Moreover, these infants tend to swallow excess air due to the open connection between the nasal and oral cavities, leading to issues such as bloating, choking, gagging, fatigue while feeding, prolonged feeding times, and an increased likelihood of spitting up and vomiting (Cooper-Brown et al., 2008).

(B) Feeding problems can arise from conditions such as central nervous system insults (e.g., brain stem injury), musculoskeletal disorders (e.g., cerebral palsy, muscular dystrophies), cranial nerve dysfunction, developmental disabilities (e.g., intellectual disabilities, pervasive developmental disorders), and other related conditions. These children have both delays and abnormal oral-motor functions, including issues with tongue and jaw movement, which leads to feeding difficulties. The common concerns reported by parents include poor sucking and lip closure, difficulties with chewing, and uncoordinated swallowing, which can lead to choking and gagging (Van Dyke et al., 1990).

(C) Feeding difficulties may stem from psychosocial factors such as inadequate environmental stimulation, dysfunctional interaction between feeder and child, and negative feeding behaviours reinforced internally or externally (e.g., selective food refusal, rumination). Additionally, emotionally based challenges like phobias, conditioned emotional responses, and depression can also contribute to feeding difficulties. Studies have indicated that behavioural problems are the primary cause of feeding disorders in 20% to 52% of children (Kovacic et al., 2021; Manikam & Perman, 2000).

(D) Feeding difficulties associated with diseases and symptoms that compromise the cardiovascular and respiratory systems, complicate the coordination of suck, swallow, and breathe during feeding. In children born with congenital heart defects, the heart condition itself is a major contributing factor to the development of secondary feeding disorders. The infant's overall medical condition had the most significant impact on the development of feeding disorders, with factors such as the duration of mechanical ventilation, the length of the hospital stay, and the post-operative need for diuretics. Children born with severe cardiac defects, requiring surgery within the first month of life are at an increased risk of developing feeding disorders by the age of two(Maurer et al., 2011). Growth problems in children with cardiac disease are often linked to poor feeding, along with increased metabolic rate, malabsorption, and breathlessness. Similar challenges are observed in children with pulmonary problems, which increase energy requirements and complicate the coordination of feeding and breathing (Singer et al., 1996). Both cardiac and pulmonary diseases involve multiple factors that can make feeding difficult and unpleasant (Field et al., 2003).

(E) Feeding difficulties associated with metabolic diseases and syndromes that interfere with the development or maintenance of normal feeding patterns (e.g., hereditary fructose intolerance or dumping syndrome) have also been identified as one of the causes.

Prevalence of feeding and swallowing difficulties

In the general population, the occurrence of severe feeding disorders at the age of two years is reported to be 1.4% (Dahl & Sundelin, 1986). This prevalence is nearly as common as in the well-known high-risk group of extremely premature infants, where feeding disorders are observed in 33% of patients at the corrected age of 30 months (Wood et al., 2003). Oral feeding difficulties are experienced by 25–45% of typically developing infants and children, and up to 80% of developmentally delayed infants and children, such as those born prematurely (Lau, 2015).

Children with neurological abnormalities were nearly six times more likely to develop feeding disorders later on compared to those without such abnormalities. The prevalence of feeding disorders is reported to be higher in children with malformation syndromes compared to those without such syndromes. This is due to associated developmental delays, oral malformations, and neurological issues, such as poor lip closure, muscle rigidity or weakness, malocclusion, a high palate, poor tongue movement, as well as aspiration and gastro-oesophageal reflux (Maurer et al., 2011).

Epidemiological research consistently indicates that the prevalence of feeding difficulties among children with neurological impairments ranges from 30% to 40%. For instance, the North American Growth in Cerebral Palsy Project found a clear association between the severity of motor impairment and the extent of feeding difficulties, with the highest incidence observed among those with severe motor impairment. (Stevenson et al., 2006).Similarly, the Oxford Feeding Study, which examined 440 children with cerebral palsy and feeding issues, identified common problems such as requiring assistance with feeding (89%), experiencing food-related choking (56%), spending over 3 hours per day on feeding (28%), dealing with constipation (26%), and encountering frequent vomiting (22%). Additionally, the study revealed that 56% of caregivers reported mealtime as a stressful experience (Sullivan et al., 2005).

Another study revealed the overall prevalence of eating and feeding issues across different levels of intellectual and developmental disabilities (IDD). Eating problems were present in 95% of children with mild IDD, 100% of those with moderate IDD, and 96% of those with severe to profound IDD. Instances of aspiration were notably more prevalent among individuals with severe IDD compared to those with moderate and mild IDD (Gal et al., 2011). Feeding problems are prevalent in children with Down syndrome, with studies indicating a frequency of 50–80% (Pipes & Holm, 1980).

Non-organic feeding disorders such as pica, infant anorexia constitutes to 15-25% of feeding difficulties in children. Sometimes feeding problems persist, and the child progresses from being picky to refusing to eat. This impacts their weight and growth, eventually leading to an eating disorder (Esparó et al., 2004). According to a report, approximately one in every 68 children at the age of eight is diagnosed with Autism Spectrum Disorder (Christensen et al., 2016).

In the Indian scenario, feeding difficulties are frequently encountered among children with cerebral palsy (CP), with estimates suggesting that anywhere from 30% to 80% of individuals with disabilities experience challenges (Aponte & Romanczyk, 2016). Another study done in children with CP found that for children in the age group of 5-8yrs, the primary feeding deficit was slow oral intake, affecting 95% of individuals. Additional issues included struggles with self-feeding (76.5%), spillage while eating (60%), aversion to solid foods (45%), risk of aspiration (35%), chewing difficulties

(35%), trouble with spoon feeding (35%), swallowing challenges (25%), difficulty with cup drinking (25%), mealtime coughing (20%), and occasional vomiting (15%) (Kamal, Iype, Rajalekshmy, & Preetha, 2014, 2014). A study done in 55 children with CP found that 78% of them had feeding deficits (Andrew & Sullivan, 2010).

Nature of feeding deficits

The nature of feeding deficits can vary depending on the underlying etiology. Some of the feeding deficits are described below:

(1) Sucking inefficiency: Inefficient sucking, marked by shorter bursts, lower pressure, and less time spent sucking, may indicate an impaired feeding ability. This could be due to disinterest, poor appetite, oral malformation, oral muscle weakness or other medical issues, or inexperience, thereby leading to poor intake (Ramsay 1995). Birth weight and gestational age showed a positive correlation to sucking ability (MacMullen & Dulski, 2000).

(2) Anterior spillage: This refers to difficulties during feeding, where food or liquid spills out of the mouth due to oro-motor impairments like poor/inadequate, lip closure restricted tongue movement etc. This condition is often observed in children with neurodevelopmental disorders or those having specific feeding disorders.

(3) Poor suck-swallow coordination: Coordination issues between sucking, swallowing and respiration may arise from the immature development of the respective muscles or due to the lack of coordination between their neurophysiological counterparts in the central nervous system.

(4) Poor chewing and biting skills- Poor chewing and biting skills in children can stem from various factors including neurological impairments (e.g., cerebral palsy), structural anomalies (e.g., cleft palate), developmental delays, sensory

processing disorders, behavioral factors, medical conditions (e.g., Gastroesophageal Reflux Disorder, GERD), and muscle weakness or coordination issues. These difficulties arise due to disruptions in the normal development and functioning of oral motor skills, inadequate exposure to diverse food textures, lack of practice, and negative feeding experiences etc All these lead to reduced intake of food and nutrient deficiency. All the above mentioned deficits along with restricted tongue movements lead to poor bolus preparation.

(5) Aspiration: This occurs in children with dysphagia, when food goes into the lungs. Chronic, recurrent aspiration can severely impact lung development, causing pulmonary issues such as recurrent wheezing, frequent pneumonias, and significant lung function impairment and scarring, which can sometimes be fatal (Tutor & Gosa, 2012).

(6) GERD or gastrointestinal issues: Clinical manifestations of GERD in children include recurrent regurgitation, vomiting, abdominal pain, heartburn, poor weight gain, and irritability. Untreated GERD symptoms can lead to a reduced quality of life for both the children and their families and may result in complications such as reflux esophagitis, failure to thrive, esophageal stricture, and Barrett’s esophagus (Malaty et al., 2008; Rosen et al., 2018). GERD can also cause decreased laryngopharyngeal sensitivity, laryngitis, sinusitis, increased frequency of silent aspiration, pulmonary infections, bronchiectasis, and apnea, as well as asthma (El-Serag et al., 2001). The children with GERD may develop oral and tactile hypersensitivity, which can make the transition to solid foods more difficult and impede the achievement of developmental feeding milestones (Strudwick, 2003).

(7) Avoidant/Restrictive Food Intake Disorder (ARFID): This is characterized by an avoidance or restriction of food intake that results in significant weight loss or failure to achieve expected weight gain in children, nutritional deficiencies, dependence on enteral feeding or oral nutritional supplements, and marked interference with psychosocial functioning. It is also associated with sensory aversions to certain foods, lack of interest in eating, or fears about the consequences of eating (Williams et al., 2015).

(8) Selective eating: This refers to a highly limited range of food intake, characterized by a narrow selection of foods consumed. Children with moderate or severe degree of food selectivity were more likely to exhibit elevated symptoms of anxiety or depression, hypersensitivity to taste and texture, have mothers with high anxiety levels, and experience family conflicts related to food. Children with severe degree of food selectivity were more likely to have a concurrent psychiatric diagnosis (such as depression or social anxiety) and an oral-motor problem affecting their eating (Zucker et al., 2015). Such children have reluctance to consume vegetables, fruits, and meats, as well as behaviours such as pica, preference for starches, and limited food choices. A diet that lacks variety can result in nutritional deficiencies if food options remain restricted, thereby posing a potential health risk associated with feeding problems (Cherif et al., 2018a). Studies have indicated a decrease in the consumption of fruits and vegetables among children with ASD, alongside a preference for foods rich in simple carbohydrate.

(9) Food refusal based on texture- This indicates refusal to eat most or all foods offered, resulting in the child failing to meet their caloric or nutritional needs (Williams et al., 2010). In a study of 349 children with feeding problems

evaluated at a hospital-based feeding program, 117 children (34%) exhibited food refusal. Oral sensory or motor issues could potentially contribute to food refusal, as children may struggle with managing chewable foods or those with mixed textures (Marshall et al., 2014).

(10) Food neophobia - Food neophobia is defined as an attitude towards food characterized by a reluctance to eat new foods and an avoidance of trying unfamiliar products. The essence of neophobic behaviour is a clear and persistent reluctance, and sometimes even fear, of tasting new foods, along with a lack of openness to different tastes or unfamiliar consistencies and colors. This rejection can also extend to previously accepted foods that appear new when presented in a different form. The mechanism behind food neophobia has not been fully understood. This phenomenon is influenced by a complex interplay of factors, with biological, psychological, and environmental elements being the most significant (Cole et al., 2017; Kozioł-Kozakowska et al., 2013; Łoboś & Januszewicz, 2019). Children with high levels of food neophobia are often more inclined to reject new foods based on individual sensory perceptions—mainly sight and smell, and to a lesser extent touch—without attempting to taste the food.

Additionally, other feeding challenges observed include rumination (repetitive regurgitation, chewing, and re-swallowing of previously ingested foods), vomiting, pica, and food theft, both during and outside of meal times. Fredericks, Carr, and Williams (1998) discovered that 6–10% of individuals with developmental disabilities exhibit rumination behaviors, which involve repeatedly regurgitating food past the airway. Rumination might occur due to physical constraints, such as being confined to a wheelchair, or other physiological issues like gastro-esophageal reflux, as well as potentially behavioral factors such as attention or access to alternative foods (Gal et al., 2011). Such behaviors pose serious risks including aspiration, suffocation, and pneumonia, which can be life-threatening.

Impact of feeding disorders on the child and the caregiver

Feeding difficulties carry significant psychosocial implications for both the child and the caregiver. While the primary function of feeding is to provide nutrition, mealtimes also offer valuable opportunities for social interaction. Challenges such as lack of independent feeding skills, extended meal durations, behavioural issues related to food, messy eating, and limited communication abilities can restrict participation in the social aspects of eating. Recognizing and addressing the psychological needs of parents or caregivers is crucial. In the Oxford Feeding study, 20% of parents reported that mealtimes were stressful or not enjoyable. Parents may struggle to entrust the care of their disabled child to others due to concerns about managing mealtime difficulties. This can significantly impact parental employment and social opportunities, leading to feelings of isolation, sadness, or depression. Such emotions may be compounded by anxiety and a sense of failure, when caregivers perceive their child as not thriving despite their dedicated efforts (Białek-Dratwa & Kowalski, 2023).

Feeding patterns begin to take shape early in childhood and are significantly influenced by the caregiver-child relationship (Crockenberg & Leerkes, 2012). Caregivers often view their ability to foster successful feeding and maintain nutritional stability as a measure of their competence (Kedesdy & Budd, 1998). Even brief episodes of noncompliance or food refusal during mealtimes can heighten caregiver stress (Silverman et al., 2020), erode parental confidence, and increase the likelihood of negative interactions between parents and children (McKee et al., 2008).

A study done in children post-heart surgery stated that 80% of the caregivers expressed feeding difficulties as one of their primary concerns following discharge. The primary challenges highlighted included infants taking an extended period to feed, consuming only small amounts per feeding, and quickly. The necessity to ensure sufficient weight gain, coupled with a demanding care regimen, sleep deprivation, and, for numerous parents, the awareness that their child might still be susceptible to sudden death, led to elevated levels of stress and vigilance. Mothers, in particular, conveyed feelings of inadequacy and voiced uncertainties about their parenting choices. Stress can impede a parent's capacity to provide adequate care for their infant, and the added difficulties of feeding a 'challenging' baby can further intensify already heightened stress levels. Parents remarked that the absence of training among local health professionals occasionally resulted in them receiving conflicting advice and reactions, which parents perceived as judgmental and consequently heightened their anxiety. In general, many parents expressed receiving less support than they had expected, especially concerning the continuation of breastfeeding and the replacement of nasogastric (NG) tubes (Tregay et al., 2017).

Hence, caregivers of children with feeding deficits face numerous challenges such as managing meal preparation, feeding sessions, and medical appointments, often experiencing high levels of stress and anxiety. These responsibilities affect family dynamics and social lives, leading to potential physical and mental health issues like fatigue and depression. Financial burdens, including medical expenses and potential loss of income, add to their struggles, though some may receive financial support through insurance, government assistance, or charities. Coping strategies, including time management, relaxation practices, and support groups, are crucial, along with resources like healthcare professionals and educational materials. Personal narratives and success stories provide unique insights, while advice for new caregivers and best practices offer practical guidance. Advocacy efforts and policy recommendations aim to improve support systems and public awareness. Interviews, surveys, and observations are essential methodologies for gathering comprehensive information, ultimately encouraging further research and policy changes to better support these caregivers and their children.

Studies that explored quality of life of caregivers of children with feeding difficulties

A study done in Ghana aimed to estimate the prevalence of malnutrition, describe the feeding difficulties experienced by children with cerebral palsy (CP) in rural Ghana, assess possible risk factors for malnutrition in this population and evaluate whether feeding difficulties and nutritional status were independently associated with caregiver quality of life. The study was a cross-sectional survey targeting children with CP and their caregivers. Children aged 2 to 12 years with a confirmed diagnosis of CP were included in the study. Caregivers were interviewed using a standardized questionnaire to gather information on socio-demographic characteristics, feeding difficulties, and caregiver quality of life (QoL). Children's nutritional status was assessed using measurements of weight, height, and mid-upper arm circumference (MUAC). Pediatric Quality of Life Inventory (PedsQL) Family Impact Module (Medrano et al., 2013)was used to assess caregiver QoL. The study revealed that approximately two-thirds of the children in the study were malnourished, with over a third being severely malnourished. The rates of underweight, wasting, and stunting were significantly higher than the national averages for children under 5 years old. A strong association was found between greater feeding difficulties and children being underweight. Caregiver QoL was significantly lower among those caring for children with severe feeding difficulties. Feeding difficulties, were significantly associated with poorer caregiver QoL (Polack et al., 2018).

Another study aimed to evaluate the impact of gastrostomy tube feeding on the QoL of caregivers of children with CP. The study specifically aimed to measure changes in caregivers' QoL in areas such as mental health, role limitations due to emotional problems, physical functioning, social functioning, and energy/vitality after the insertion of a gastrostomy tube in their child. The study involved 57 Caucasian children with CP (28 females, 29 males; median age 4 years and 4 months). Gastrostomy tubes were inserted in the children, and the quality of life of their carers was assessed at baseline, and then at 6 and 12 months after the procedure. The Short-Form 36 version II (SF-36 II) was used to measure the QoL of the carers. This tool assesses multiple domains, including mental health, role limitations due to emotional problems, physical functioning, social functioning, and energy/vitality. The results of the study highlighted significant improvements in the QoL of carers following the insertion of gastrostomy feeding tubes in children with CP. By 12 months, there were significant improvements in mental health, social functioning, and energy/vitality scores. Carers reported a substantial reduction in the time spent on feeding, which contributed to the observed improvements in QoL. The ease of administering medications and reduced concerns regarding the child's nutritional status were noted as significant factors enhancing the carers' QoL (Sullivan et al., 2004).

Another study aimed to characterize the medical diagnoses and feeding impairments of children diagnosed with feeding disorders, examine the quality of life of these children and the impact on their caregivers, and compare quality of life differences between children with feeding disorders and those with other conditions.

The study utilized a cross-sectional design to examine health conditions, impairments, and QoL in children with pediatric feeding disorders (PFD). Conducted in the Greater Boston Area between October 2017 and June 2018, the study enrolled 50 children aged 2-5 years diagnosed with PFD. Pediatric QoL Generic Core Scales 4.0 (Medrano et al., 2013) and Feeding/Swallowing Impact Survey (FS-IS, Lefton-Greif et al., 2014) were administered. The study found a diverse range of medical diagnoses and feeding impairments among the children. The most common diagnoses were neurological/genetic disorders, while the most common impairments were related to oral sensory processing and limited volume intake. Children with PFD exhibited lower quality of life scores compared to children with other chronic conditions. Feeding difficulties had significant negative impacts on both children and their caregivers. Caregivers of children with PFD experienced high levels of stress and significant impact on family functioning. The findings also underscores the need for tailored management approaches that address both the medical and quality of life aspects of PFD (Simione et al., 2023).

A study focused on the impact of Eosinophilic Esophagitis (EoE) on children's eating behavior and the QoL of their caregivers. The study prospectively enrolled 80 caregivers of children aged 6 to 18 years, presenting at a multidisciplinary Eosinophilic Gastrointestinal Disorders clinic and the Gastroenterology clinic. This group included 42 caregivers of children diagnosed with EoE and 38 caregivers of children without EoE (control group). EoE was defined according to the 2011 consensus guidelines, which required children to have ≥ 15 eosinophils per high power field in esophageal biopsies and at least one symptom of esophageal dysfunction, excluding other causes of esophageal eosinophilia (Hiremath et al., 2019). The study found that while caregivers' perceptions of eating behaviors did not significantly differ between children with Eosinophilic Esophagitis (EoE) and those without, caregivers of children with EoE reported significantly higher concerns and challenges related to feeding, particularly regarding breathing and choking during meals. These concerns negatively impacted their quality of life, highlighting the need for comprehensive care that addresses both the physical and emotional aspects of managing EoE.e FS-IS (Lefton-Greif et al., 2014).

Tools to assess quality of life of caregivers of children with feeding and swallowing difficulties

Caregiver quality of life is a neglected area and is highly under researched. A literature review revealed that the questionnaires to assess caregiver QoL and burden is restricted in the area of paediatric dysphagia, while there are a few of them that assess caregiver quality of life and the associated burden, while caring for adults with dysphagia. These questionnaires are described below. Colodny (2008) introduced and validated the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ), designed to evaluate how well caregivers adhere to Speech-Language Pathologist (SLP) recommendations for individuals with dysphagia. The questionnaire comprises items addressing three main factors: quality of life considerations, disagreement with SLP guidance, and avoidance of implementing feeding and dietary modifications. Findings from the study indicated that caregivers with higher incomes and fewer visits to SLPs tended to have a more distant relationship to the patient and placed greater emphasis on QoL concerns over SLP directives. While the CMDQ primarily focuses on assessing compliance with SLP recommendations, it indirectly sheds light on dysphagia-related caregiver burden through select statements (Colodny, 2008).

Shune et al. (2020) describe the development and initial validation of the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) screening tool in their article. This tool, comprising 26 items, was created by a team of dysphagia research experts and divided into two subscales: Part A and Part B. Part A consists of ten items that assess behavioural and functional changes in caregivers' lives resulting from dysphagia-related caregiving, while Part B comprises sixteen items that measure dysphagia-specific perceived stresses experienced by caregivers. Responses to each item are recorded as 'yes' or 'no', with 'yes' scoring 1 and 'no' scoring 0. Higher scores on both subscales indicate a greater dysphagia-specific burden for the caregiver. Additionally, each subscale includes an additional question aimed at identifying the most burdensome issues indicated in the statements (Shune et al., 2020).

Jain and Jagtap (2021) aimed to develop a Marathi tool called Quality of Life Due to Dysphagia Questionnaire for Caregivers of Individuals with Dysphagia (QOLC-M) for assessing the feelings, attitudes, and quality of life of caregivers providing care to individuals with dysphagia. The questionnaire's three sections covered 42 statements or questions related to "activities of daily living and social (ADLS)," "feelings and attitudes (FA)," and "feeding." The ADLS section comprised 14 statements assessing the dysphagia's impact on caregivers' mealtimes, daily activities, social participation, leisure times, job, and finances. The FA section included 12 statements exploring caregivers' attitudes and emotions towards dysphagia and its associated concerns. The feeding section consisted of 16 statements, with six common statements for caregivers feeding their care recipients and five specific statements each for oral and tube feeders. Their findings indicated that caregivers experienced moderate to severe negative impacts on their everyday activities, socialization, feelings, attitudes, and faced significant difficulties during feeding. The questionnaire demonstrated statistically significant reliability and internal consistency, making it a valuable tool for measuring dysphagia-related caregivers' quality of life (Jain & Jagtap, 2022).

The Caregiver Analysis of Reported Experiences with Swallowing Disorders scale (CARES, Arakkal, 2023) is a tool developed to assess the dysphagia-specific caregiver burden. It consists of 26 items divided into two subscales: Part A and Part B, with ten and sixteen items, respectively. This scale helps in identifying and tracking the needs of caregivers who manage individuals with swallowing disorders, particularly focusing on the emotional, physical, and financial challenges they face. The scale was standardized and validated on sixty caregivers of adults with dysphagia. The reliability testing of the translated CARES tool showed good internal consistency and reliability, with Cronbach's alpha values 1.000 for Part A, 0.998 for Part B, and 0.999 for the total scale. The test-retest reliability was assessed by readministering the CARES tool to about 10% of the participants after two weeks. The correlation coefficient for subscale 1 (Part A), subscale 2 (Part B), and the total scores was found to be 1.00, 0.986, and 1.00, respectively. This instrument assesses the caregiver burden associated with managing dysphagia, providing robust and consistent results across different settings and populations.

With reference to assessing the QoL of caregivers of children with feeding and swallowing problems, the literature review revealed the existence of only one questionnaire, the Feeding/Swallowing Impact Survey (FS-IS, Lefton-Greif et al., 2014a), which is an inventory (an 18-item tool). FS-IS has been trans-adapted to various languages as described below:

(A) The Turkish version of FS-IS was clinically validated on 117 children diagnosed with CP between the age range of 1-4 years (Serel Arslan et al., 2018). Swallowing severity was measured with Videofluoroscopic Swallowing Study and penetration and aspiration severity was determined according to the Penetration-Aspiration Scale (PAS). Caregivers whose children had aspiration reported worse scores in the T-FS-IS total and its subscales, compared with caregivers whose children without airway aspiration. It had a reliability value of 0.99 and average FS-IS score of 2.63. The scale is thereby considered as a potent tool to measure the impact of swallowing disorders on caregivers of children with CP.

(B) The Brazilian Portuguese version of FS-IS was clinically validated by Rama et al., (2022): on 95 caregivers of children with dysphagia grouped as mild, moderate and severe dysphagia based on Paediatric Dysphagia Evaluation Protocol (PDEP). The age range of children were 0-18 years. The tool was successfully concurrent validated with PEDS-QL™ Family Impact Module (FIM, Davis et al., 2010).The internal reliability value was 0.99 and the average score regarding caregiver quality of life was 2.63. There was a notable correlation between Pt–Br–FS–IS scores and the classification of moderate to severe dysphagia. As the severity of dysphagia increased, the impact on the caregiver's quality of life also increased.

(C) Another study aimed to culturally adapt and validate FS-IS in the South African context (Bestenbier et al., 2021). The caregivers of 32 children between 1 to 3 years with Feeding and Swallowing Difficulties (FSD) such as the need for non-oral feeds, oral feeds with specific modifications, and behaviors such as picky or selective eating etc. were recruited for the study. The results revealed an average score of 2.54, which was the measure of impact on caregiver quality of life and a reliability value of 0.83. The study underscores the significant impact of feeding and swallowing difficulties on caregivers' quality of life. Issues such as worry, stress, and alterations in daily activities were commonly reported.

To summarize, the review of the literature provided an insight into the burden experienced by caregivers of children with dysphagia, which can stem from various underlying causes. These studies shed light on difficulties experienced and concerns raised by caregivers, while feeding children with feeding difficulties. Despite the increasing prevalence of dysphagia in children over the years in India, there remains a scarcity of tools designed to quantify quality of life accurately in caregivers of children. In the Indian context, particularly in languages like Kannada, there is a notable absence of screening tools for assessing caregiver quality of life related to feeding or swallow deficits, especially in the paediatric population. Keeping this in view, the present study was planned. The methods employed in this study has been described in the next chapter.

Chapter III

Method

The current study aimed to trans-adapt the FS-IS screening tool into Kannada and validate the tool on caregivers of children with feeding or swallow deficits secondary to cerebral palsy. The primary objectives of the study were to adapt and translate the caregiver quality of life screening tool FS-IS to Kannada and to determine the validity (content, clinical and construct validity) and reliability (test-retest reliability) of the constructed Kannada version FS-IS screening tool. The secondary objectives of the study were to check for any association between several caregiver-related (such as age, gender, socioeconomic status, relationship status, and duration of caregiving services) and care recipient-related (such as age, dependency status, feeding status, severity of motor impairment) variables and the scores on Kannada version of the FS-IS tool.

3.1 Research Design

An analytical cross-sectional research design was used in this study.

3.2 Ethical Consideration

The study was conducted in accordance with the ethical standards for Bio-behavioral Sciences for human subjects established by the AIISH ethical committee. 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.

3.3 Tool Development and Testing

The study was conducted in four phases:

Phase 1: Seeking Permission from the Original Authors Prior to Trans Adaptation of the FS-IS Questionnaire.

Permission was sought through email communication from the original authors, who developed the FS-IS screening tool, to translate, modify and adapt the tool as required. The email regarding the same has been attached as Appendix I.

Phase 2: Translation of FS-IS from English to Kannada

The original version of the FS-IS (Lefton-Greif et al., 2014) questionnaire was translated into Kannada, complying with the standard WHO guidelines (2020) for the translation and adaptation of tools. The below listed steps were followed in this study:

1. Forward translation
2. Expert panel review
3. Back-translation
4. Pretesting and cognitive interviewing
5. Final version

Forward Translation **-**The FS-IS questionnaire was translated from English "source" to Kannada language "target". Forward translation was performed by two literates who were knowledgeable in the field and had Kannada as their native language and English as their second language. Translators were instructed to aim at the conceptual equivalent of a term or phrase, not a literal translation, i.e., not a word-for-word translation. They focused on the meaning of the original term/phrase and tried to translate it in the most admissible manner. Following were the instructions given to the translators:

- The translated questions should be simple, clear, concise, and to the point.

- Lengthy sentences with numerous clauses should be avoided.
- The target language should aim at the general population, not professional ones. The comprehensibility of the tool/questionnaire by the respondents for whom the tool is being translated should be the focus.
- Age and gender issues of applicability should be considered and terminology that may be offensive to the target group may be avoided.

Expert Panel Review-A panel of four bilingual individuals fluent in English and Kannada were constituted. The expert panel members included three speech-language pathologists (SLPs) with a minimum of three years of clinical experience with dysphagia, and a non SLP, who was proficient in the Kannada language. This stage aimed to recognise vague statements/concepts in the translation and to sort out any disparities between the forward translation and existing cross versions of the questions. The expert panel questioned specific terms and suggested suitable alternatives. Two of the SLPs who reviewed the questionnaire suggested changing certain terms, adding or deleting terms that seemed inappropriate, and reordering certain statements. These suggestions were made for statements 3,5 in subscale1, statement 4 in subscale 2 and statement 1 and 5 in subscale 3. For example, the term / ɑːɟæʂɚʋæɠʊʈæɖɚ/ was changed to / susta:guttade / in statement 5 of subscale 1. The term / tondərejindɑ / was inserted to statement 4 in subscale 2. The title of the questionnaire was changed from mɑkæɭɪgə ɑːhɑːɾæ ʈɪnɪsʊvæ ɑʈʰævɑ mækkɑɭɑ ɑːhɑːɾæ səvɑnə/ nʊŋʊvɪkɟə ʈɔ̃nɖɑɾəɠæɭʊ poʃækɑːrɑ məɭə ʊnʈ̩ʊmɑːdʊvɑ pæɾɪɲɑmæɠɑɭʊ / to / makkaɭige a:ha:ra unisuvike/ nunguvikəja tondaregaɭu poʃaka:ra məle untuma:duvɑ parina:ma samIkʃe/ etc. The other SLP suggested rephrasing of statement 1 and 5 in subscale 3, if deemed necessary after the cognitive interviewing or pilot study. The fourth member of the review panel pointed out no disparities or modifications. This procedure constructed a complete translated version of the questionnaire.

Backward Translation-Using the same method described in the initial step, another independent translator, who was blinded to the questionnaire, translated the tool back from Kannada "target" to the English language "source". The discrepancies present in the previous step regarding simplification and reframing of the specific questions were discussed with the participants involved in the earlier steps. The necessary modifications were made as required till a generally acceptable version is obtained.

Pretesting and cognitive interviewing- A pre-test was conducted on five primary caregivers of children with cerebral palsy. The questionnaire was given to the participants, who read, understood, and interpreted the questions. Respondents suggested including simpler sentences or words that aligned better with their experiences and pointed out unclear questions, along with any additional burdens or complications they faced. They returned the proposed modifications from the pretest to the experts, who then re-discussed, reformulated the unclear items, and finalized the questionnaire. Based on the caregivers' suggestions, statements 1 and 5 in part III were rephrased and simplified

Development of the Final version- The final version of the questionnaire in Kannada was prepared after incorporating all the suggestions from the reviewers.

Phase 3: Validation of the translated questionnaire

In this phase, the validation process was done in the following steps.

Step 1- Content validation -For content validation, three expert SLPs proficient in Kannada and specialized in dysphagia, were asked to evaluate the translated screening tool. They were asked to rate items/statements on a three-point Likert scale (0-no fit, 1-neutral and 2-excellent fit) in terms of ambiguity, transparency, cultural appropriateness, and representativeness. Table 3.1 depicts the parameters used for the content validation along with the rating scale.

Table 3.1

Parameters for content validation along with the rating scale

Parameters	Rating Scale		
	0-No Fit	1-Neutral	2-Excellent Fit
Clarity	Not clear	Needs some revision	Very clear
Simplicity	Not simple enough	Needs some revision	Very Simple
Relevance	Irrelevant	Needs some revision	Very Relevant
Framing of the item	Incomplete framing	Needs some revision	Well Framed
Applicability	Inapplicable	Needs some revision	Highly applicable
Appropriateness	Inappropriate	Needs some revision	Highly Appropriate

Questions were modified only if two judges rated it as ‘0-No fit’ or ‘1-Neutral’. Two of the three SLPs rated ‘2-Excellent Fit’ for clarity, framing of the item, relevance applicability and appropriateness for all the 18 statements. However, ‘1-Neutral’ was rated for simplicity for 2 statements (Statement 10 and 12). The other SLP rated ‘1-Neutral’ for all the statements. Since all the judges rated ‘1-Neutral’ for simplicity, the questions were reviewed for simplicity once again and the necessary changes were incorporated. In addition, five primary caregivers of children with paediatric feeding disorders were included to determine the clarity, simplicity, appropriateness, and framing of the item of translated version of the scale. They also rated the items/statements on a three-point Likert scale based on the same parameters. Statements I and V in part III were requested for simplification. The necessary changes such simplification and rephrasing were done and the final translated version of the screening tool were prepared.

The final Kannada version-FS-IS (FS-IS-K) had 18 items/statements with three subscales, viz. Daily Activities (5 items), Worry (7 items), and Feeding Difficulties (6 items). It uses a 5- point Likert scale ranging from a score of “1” indicating never to a score of “5” indicating almost always. The same has been attached in Appendix II. The original English version of FS-IS has also been attached as appendix III.

Step 2- Pilot study- Five primary caregivers of individuals with feeding/ swallowing disorders secondary to cerebral palsy who met the inclusion criteria were recruited in the pilot study. The translated version of the screening tool was provided for filling it up. The participants were able to fill out the translated tool within 5 to 10 minutes, were able to understand the 18 questions and provide appropriate responses.

Step 3- Clinical validation-Following the pilot study, the questionnaire was administered on the primary caregivers of children with feeding deficits secondary to cerebral palsy, as a part of establishing clinical validity.

Participants- The participants for the current study included caregivers of children with feeding deficits secondary to cerebral palsy in the age range of 2-18 years, who were recruited from the Department of Clinical services and Preschool training center of AIISH and various other speech and hearing centres and special schools, in Mysuru, Karnataka, India. The children recruited for the study were enrolled for speech therapy, physiotherapy and/or special education in the concerned facilities. Primary caregivers aged 18 years and above and who were providing caregiving services for at least six months were recruited for the study. The caregivers were required to be able to read and understand Kannada. Primary caregivers with any other health issues or psychiatric illnesses were ruled out informally during the interview, and those who had prior experience in taking care of the needs of individuals with dysphagia were excluded from the study. The socioeconomic status of the participants was determined based on the modified Kuppuswamy socioeconomic scale (Sood & Bindra, 2022). A total of 60 participants (male:3, female:57) with a mean age of 34.63± 7.55 years completed the questionnaires. Out of the sixty primary caregivers-56 were mothers, 2 were fathers and 1 was grandmother. Care recipients were children with a mean age of 6.28±3.709. The mean age of identification of their feeding deficits were 2.01±1.68. The demographic details of the participant caregivers and their care recipients are given in Tables 3.2 and 3.3.

Table 3.2

Demographic details of the caregivers (N=60)

Demographic Data	Number of participants (n)
Gender	
Male	3
Female	57
Socioeconomic status	
Upper class	4
Middle class	32
Lower class	24
Education of the caregiver	
High School	24
Diploma	5
Graduate	28
Honours	3

Table 3.3

Demographic details of the care recipients

Demographics	Participants
Care Recipient Status	
Capable of selfcare	4
Capable of limited selfcare	24
Fully Dependent	32

Step 4-Construct Validation-Construct validity was established by administering 'The Burden of Persons with Aphasia on the caregivers' (Swati, 2008). This scale offers a brisk screening and safe dependable method to recognise caregiver burden. This includes 40 questions in seven domains, viz. Psychosocial, Emotional, Personal Relationship, Care responsibility, Caregiver health related, Communication expectation, and Caregiver communication style. Each question has a set of five choices from strongly agree to strongly disagree. Though it is standardized on aphasia population, most of the domains mentioned are in general to any caregiver burden assessment. Hence the questions which tap the caregiver-child difficulties or burden specifically were administered.

The Feeding handicap Index (FHI, Shabnam & Swapna, 2023) was administered. It is an indirect measure to assess the severity of feeding/ swallow impairment. 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. The responses of the participants on this clinician-administered tool was assessed on a 3-point Likert-type scale ranging from 0 to 3 (0: never has the problem, 1: sometimes has the problem 2: always has the problem).

Procedure

The data was collected face-to-face after explaining the need for the study and getting their consent in a quiet room with no distractions. There were five forms to be filled out during the evaluation of a participant, including the consent form, the demographic data sheet, the Kannada version of the FS-IS questionnaire (FS-IS-K), the Kannada version of 'The Burden of Persons with Aphasia on the caregivers' and the Feeding Handicap Index (FHI). The participants filled out all the other forms except the demographic form and the FHI. The participants were explained about the identity anonymous policy and withdrawal anytime during the study option. The written consent of the participants was collected after explaining the purpose and details of the study (Appendix IV). The demographic data of the participants such as caregiver's and care recipient's age, caregiver's and care recipient's gender, age of identification of feeding deficits, caregiver education, care recipient dependency status, socioeconomic status were collected and detailed in the demographic form. The modified Kuppuswamy socioeconomic scale (Sood & Bindra, 2022) was used to classify the caregivers into different levels of socioeconomic status (SES).

The FHI was administered to assess the severity of feeding/ swallow impairment. The FS-IS-K and the Kannada version "The Burden of Persons with Aphasia on the caregivers" questionnaire was provided to the target group to fill in. A total of 10-15 minutes were taken for the forms to be filled out by the participants.

Step 5-Test-Retest Reliability

The test-retest reliability was conducted on about 10% (n=6) of the participants after two weeks of completion of the initial data collection. The FS-IS-K questionnaire was administered again after seven days, to a few of the randomly selected participants (n=6) after getting their consent.

3.4 Statistical Analysis

The total scores of the FS-IS-K (subscale scores, total score and the average total score), the total score of FHI and the total score of the Kannada version- The Burden of Persons with Aphasia on the caregivers questionnaire were computed and tabulated for each participant. All the statistical analyses to be performed were carried out using SPSS software, version 26 (Statistical Package for the Social Science package, version 26). Normality testing using the Shapiro-Wilk test was done prior to the statistical analysis. Descriptive statistics was computed for the total scores and the scores of subscales 1, 2 and 3 of FS-IS-K. The construct validity was determined using Spearman's rank-order correlation. Test-retest reliability or internal consistency analysis was established by calculating Cronbach's alpha. The participant (caregiver) and their care recipient variables were analysed for their influence on the feeding specific caregiver quality of life scores using appropriate statistical methods, based on whether the data under the variable was continuous or categorized into groups. The results obtained have been discussed in the next chapter.

Chapter IV

RESULTS

The current study aimed to adapt and translate the Feeding/Specific-Impact Survey (FS-IS) screening tool in Kannada and validate the tool on caregivers of children with feeding deficits secondary to cerebral palsy in the age range of 2-18 years. FS-IS is a tool to assess the impact of feeding specific caregiver quality of life. The study aimed to achieve several objectives, which include trans-adaptation of FS-IS into Kannada, to conduct content, clinical, and concurrent validation of the tool, to assess test-retest reliability, and to explore the relationship between various caregiver variables such as age, socioeconomic status, education, various care-recipient variables such as age, gender, age at which feeding deficits were identified, dependency status and the feeding-specific quality of life of caregiver. Though other demographic details such as medical conditions/comorbid issues of the care recipient, relationship with caregiver, gender of caregiver, duration of feeding intervention, duration of caregiving etc. were gathered, they were not included for statistical analysis as the sample size was not sufficient.

The original English version of FS-IS was translated by two native speakers of Kannada and then adapted and content validated by a team of three speech-language Pathologists (SLPs), specialized in deglutition and by five primary caregivers of children with feeding and/or swallowing disorders with adequate proficiency in Kannada. The final version of FS-IS -K was developed after simplifying and reframing certain questions. The FS-IS-K had 18 items/statement categorized into three subscales with a 5- point Likert scale ranging from a score of “1” indicating never to a score of

“5” indicating almost always. The three subscales in FS-IS-K were Daily Activities (5 items), Worry (7 items), and Feeding Difficulties (6 items).

The FS-IS-K was administered to sixty primary caregivers of children with feeding deficits secondary to cerebral palsy (CP). The Kannada version of The Burden of Persons with Aphasia on the caregivers’ (Swati, 2008) was also administered to assess the concurrent validity. The Feeding Handicap Index (FHI, Shabnam & Swapna, 2023), which is an indirect measure to assess the severity of dysphagia was also administered.

The total, subscale and the average total scores of the FS-IS-K, scores of FHI and the Kannada version of ‘The Burden of Persons with Aphasia on the caregivers ’ and data on all other independent variables obtained were tabulated and entered into the SPSS software (version 26) for statistical analysis. Descriptive statistics were computed for the total scores and the scores of the subscales of the adapted FS-IS-K tool. Spearman’s rho correlation coefficient was computed to verify the assumption that greater feeding specific caregiver quality of life was associated with more severe swallowing issues established using the FHI tool. Similarly, the association between the general caregiver burden scores, measured using the Kannada version of ‘The Burden of Persons with Aphasia’ and the feeding specific caregiver quality of life was assessed.

To assess the effect of different caregiver and care recipient variables on the feeding specific caregiver quality of life, each participant's total and subscale scores of the FS-IS-K were compared or correlated with the data obtained for these variables using appropriate statistical methods. The Shapiro-Wilk test performed revealed that the data was non-normally distributed. Hence, nonparametric tests such as Kruskal-Wallis and Mann-Whitney U tests were performed accordingly, depending on the number of categories under each independent variable, to analyse the association between the dependent variable (total and subscale scores of the adapted FS-IS-K) and all the independent variables (caregiver related and care recipient related variables). The parameters with a p-value less than 0.05 were considered to be significantly associated with feeding-specific caregiver quality of life.

Test-retest reliability was also assessed on 10% of the participants (n=6) after two weeks of initial data collection. Test-retest reliability analysis was done by calculating Cronbach's alpha. Generally, a correlation coefficient or an alpha coefficient of ≥0.70 is considered to be reliable (Taber, 2018). The results of the current study have been described in the sections below.

4.1 Performance on the Trans-adapted FS-IS-K Tool

Descriptive statistics was computed for the total scores and the subscale scores of FS-IS-K. The mean (M) and standard deviation (SD) for the total scores on the FS-IS-K was 45.77±21.98. The mean and SD for subscale 1, which evaluated the impact of caregiving on activities of daily living was 15.10±6.98, for subscale 2, which measured worry related to caregiving was 17.62± 9.22, and subscale 3, which assessed difficulties associated with feeding was 13.00±7.83. The average total score of FS-IS-K was 2.54. This was calculated by summing the response scores of all the 18 items/statements and then dividing the total score by 18. The average total score also represents the impact of feeding-related problems on the caregiver's quality of life. The average total scores and the mean scores suggest that the primary caregivers of children with feeding deficits secondary to cerebral palsy, experienced a considerable degree of decrement in quality of life in terms of worry for their child, feeding related stress and perceived stress affecting their activities of daily living.

The percentage of responses from the caregivers for each statement in the trans-adapted FS-IS tool was computed. The table 4.1 indicates the number (n) and percentage (%) of participant responses for each statement in the adapted questionnaire.

Table 4.1

Frequency (n) and percentage (%) of responses of the participants for each statement in the trans-adapted FS-IS-K tool

		n(%)	n(%)	n(%)	n(%)	n(%)
	Statements	**1-Never**	**2-Almost never**	**3-Half the time**	**4-Very Often**	**5-Almost always**
Subscale 1 Daily Activities	Statement 1	13 (21.67)	12 (20)	7 (11)	11(18.33)	17 (28.33)
	Statement 2	18 (30)	9 (15)	5 (8.33)	10 (16.66)	17 (28.33)
	Statement 3	19 (31.66)	6 (10)	6 (10)	9 (15)	19 (31.66)
	Statement 4	16 (26.66)	11 (18.33)	7 (11.66)	7 (11.66)	19 (31.66)
	Statement 5	16 (26.66)	10 (16.66)	9 (15)	12 (20)	13 (21.66)
Subscale 2 Worry	Statement 6	11 (18.33)	12 (20)	6 (10)	7 (11.66)	24 (40)
	Statement 7	26 (43.33)	10 (16.66)	3 (5)	7 (11.66)	14 (23.33)
	Statement 8	23 (38.33)	10 (16.66)	5 (8.33)	6 (10)	16 (26.66)
	Statement 9	26 (43.33)	7 (11.66)	8 (13.33)	6 (10)	11 (18.33)
	Statement 10	24 (40)	10 (16.66)	6 (10)	4 (6.66)	16 (26.66)
	Statement 11	23 (38.33)	13 (21.66)	4 (6.66)	8 (13.33)	12 (20)
	Statement 12	25 (41.66)	13 (21.66)	3 (5)	5 (8.33)	14 (23.33)
Subscale 3 Feeding	Statement 13	32 (53.33)	11 (18.33)	1 (1.6)	4 (6.66)	13 (21.66)
	Statement 14	31 (51.66)	13 (21.66)	2 (3.33)	3 (5)	11 (18.33)
	Statement 15	33 (55)	7 (11.66)	3 (5)	6 (10)	11 (18.33)
	Statement 16	24 (40)	11 (18.33)	6 (10)	7 (11.66)	12 (20)
	Statement 17	25 (41.66)	12 (20)	5 (8.33)	4 (6.66)	14 (23.33)
	Statement 18	27 (10)	10 (16.66)	3 (5)	7 (11.66)	13 (21.66)

Subscale 1 has 5 statements (1-5), subscale 2 has 7 statements (6-12) and subscale 3 has 6 statements (13-18)

In Subscale 1, the highest percentage of participants affirmed statement 3 and statement 4 (both n=19, 31.66%), which addressed "leaving the child with others to feed them" and "difficulty for the family to make plans or go out to eat." Statements 1 and 2 (both n=17, 28.33%) followed closely, reflecting "difficulty managing a job or higher education" and "challenges in seeking help from others for feeding." The lowest percentage of responses was for statement 5 (n=6, 10%), which reported "difficulty leaving the child with others due to feeding concerns."

In Subscale 2, the highest affirmative responses were for statements 8 and 10 (both n=26, 43.33%), which reported "caregiver’s worry about others' reactions to the child's feeding problem" and "worry that the child will never eat and drink like other children." The next highest response was for statement 6 (n=24, 40%), which concerned "whether the caregiver is doing enough to help their child with feeding." The lowest response was for statement 7 and 12 (n=3, 5%), which involved "worry that the child’s feeding problem will affect other family members" and “worry that does not get enough to eat or drink”.

In Subscale 3, the highest response was for statement 17 (n=14, 23.33%), which related to "difficulty feeding the child due to differing opinions from family members or professionals regarding the child’s feeding." The lowest response was for statement 14 (n=2, 3.33%), which concerned "difficulty feeding the child due to uncertainty about

4.2 Concurrent validation of the trans-adapted FS-IS-K

The concurrent validity was carried out by correlating the total scores of the FS-IS-K tool with the total scores of the Kannada version of The Burden of Persons with Aphasia on the caregivers. The Spearman’s Rank Order Correlation was administered for the same purpose. The subscale 1, subscale 2, subscale 3 and the total scores of FS-

IS-K significantly correlated with the total scores of the Kannada version of The Burden of Persons with Aphasia on the caregivers, yielding a correlation coefficient of 0.44 (p=0.00), 0.45 (p=0.00), 0.45 (p=0.00) and 0.49 (p=0.00) respectively, suggestive of a average (moderate) positive correlation (Table 4.2). These results indicated a decrease in feeding-specific quality of life correlated with a greater general caregiver burden. In view of these findings, the hypothesis that there is no association between feeding specific caregiver quality of life and the general caregiver burden scores as measured using the Kannada version of 'The Burden of Persons with Aphasia on the caregivers' is rejected.

FHI was used to determine the severity of feeding disorder indirectly. The results of the analysis revealed a statistically significant average (moderate) positive correlation with the FS-IS-K subscale 1, subscale 2 and subscale 3 scores, with a correlation coefficient of 0.59 (p=0.00), 0.60 (p=0.00), 0.48 (p=0.00) respectively. The total score of the FS-IS-Kand the FHI levels correlated with a coefficient of 0.62 (p=0.00). As the FHI level increased, the FS-IS-K scores (total and subscale scores) also increased. This indicated that the feeding-specific quality of life was found to decrease with increase in feeding difficulties. In view of these findings, the hypothesis that there is no association between feeding specific caregiver quality of life and severity of feeding and swallowing issues established using the Feeding Handicap Index tool is rejected. The results of Spearman's rank order correlation is depicted in Table 4.2.

Table 4.2

Results of Spearman's Rank Order correlation between the FS-IS-K total, subscale 1, and subscale 2 and subscale 3 scores and the FHI levels and The Burden of Persons with Aphasia on the caregivers Scale Kannada version (N=60)

FS-IS-K	FHI		The Burden of Persons with Aphasia on the caregivers	
	Correlation coefficient, r	p-value	Correlation coefficient, r	p-value
Subscale 1	0.59	0.00*	0.44	0.01*
Subscale 2	0.60	0.00*	0.45	0.00*
Subscale 3	0.48	0.00*	0.45	0.00*
Total score	0.62	0.00*	0.49	0.00*

** $p<0.01$.*

4.3 Test-retest reliability and Internal reliability

The trans-adapted FS-IS-K tool was re-administered on 10% of the total participants (n=6) after two weeks of their initial response collection. The scores of initial responses and the test-retest responses of the participants were calculated, tabulated and then fed into SPSS software (version 26) for reliability analysis. Spearman's Rho was calculated for the total scores of the tool, before and after two weeks of initial response. The correlation coefficient of the total FS-IS-K score was found to be 0.99 (p=0.00), indicating excellent level of test-retest reliability. This suggests that the test produces nearly identical results when administered at different points in time, indicating excellent stability and reliability. The Cronbach's Alpha was found to be 0.89 across the three subscales revealing a good internal consistency among statements included in the tool. This suggests that the test items/statements were highly consistent and measure the same construct very reliably.

4.4 Association between the trans-adapted FS-IS-K and the caregiver and care recipient-related variables

Correlation analysis was carried out to identify the association between total and subscale scores of the trans-adapted FS-IS-K tool and different caregiver variables (such as age, education, socioeconomic status) and care recipient variables (age, age of identification of feeding deficits, and dependency status). Only these variables were considered as there was insufficient sample size with regard to the other variables. The results revealed that the variable contributing to the caregivers' burden was the care-recipient's age. The other caregiver variables, such as age, education, socioeconomic status, and care recipient variables, such as gender, age of identification of feeding deficits were found to have no significant association with feeding-specific caregiver quality of life. Thus, the hypothesis that there is no association between caregiver age, education, socioeconomic status, care-recipient age, gender, age of identification of feeding deficits, dependency status and feeding specific caregiver quality of life, is only partially accepted. The results of the analysis performed are given below.

4.4.1Caregiver related variables

4.4.1.1 Correlation between the caregiver age and the FS-IS-K scores

The total and subscale scores of the FS-IS-K tool were calculated for each participant and subjected to correlational analysis across their ages. Spearman's Rank Order correlational analysis was carried out for the same. The results revealed that the correlation between the two variables was not significant ($p > 0.05$) for the total scores and subscale scores (Table 4.3). The correlation coefficient for subscale 1, subscale 2, subscale 3 and total scores were 0.06 (p=0.65), 0.02 (p=0.88), -0.04 (p=0.74) and 0.03 (p=0.84) respectively. The findings suggested no correlation between the age of the caregiver and the feeding specific caregiver quality of life experienced by the caregiver. There was no effect of the caregiver's age on the experienced difficulties in daily activities, worry and feeding difficulties as a result of their caregiving to children with feeding difficulties. The quality of life was affected

for all the caregivers of children with feeding difficulties, irrespective of their age. The results of Spearman's Rank Order correlation between the caregiver age and the FS-IS-K scores have been depicted in Table 4.3.

Table 4.3

Results of Spearman's Rank Order correlation between the caregiver age and the FS-IS-K scores (N=60)

FS-IS-K	Correlation coefficient, r	p value
Subscale 1	0.06	0.65
Subscale 2	0.02	0.88
Subscale 3	-0.04	0.74
Total Score	0.03	0.84

4.4.1.2 Comparison of FS-IS-K scores across socioeconomic status

The caregivers and their care recipients were classified into different socioeconomic status (SES) levels, based on the modified Kuppuswamy socioeconomic scale (Sood & Bindra, 2022). For ease of statistical analysis, the data collected were grouped into three categories viz. Upper Class, Middle Class and Lower Class. There were 4 participants under Upper Class, 32 under Middle Class and 24 under Lower Class. The results of descriptive statistical analysis are given in Table 4.4. The Kruskal-Wallis test was done to determine any significant difference between the FS-IS-K scores (subscale scores and total) across different levels of SES. The chi-square values were found to be 4.18 (p=0.12), 3.16 (p=0.21), 3.90 (p=0.14) and 3.58 (p=0.17) with 2 degrees of freedom for subscale 1, subscale 2, subscale 3 and total scores respectively (Table 4.4). The test results revealed no significant difference between the FS-IS-K scores across different levels of SES. However, a slightly greater burden was observed for the upper class among the three SES groups based on mean, even though it was not statistically significant.

Table 4.4

Mean, standard deviation (SD)and results of the Kruskal-Wallis test for the FS-IS-K scores across different socioeconomic status (N=60)

FS-IS-K section	Mean (SD)			x^2 (df=2)	p-value
	Upper	Middle	Lower		
Subscale 1	20.00 (4.54)	13.53 (6.30)	16.38 (7.71)	4.18	0.12
Subscale 2	22.50 (6.65)	15.41 (7.02)	19.75 (11.41)	3.16	0.20
Subscale 3	11.25 (6.39)	11.00 (5.92)	15.96 (9.47)	3.90	0.14
Total Score	53.75 (15.52)	39.94 (17.05)	52.21 (26.72)	3.58	0.17

4.4.1.3 Comparison between FS-IS-K scores and educational levels

The caregiver's educational backgrounds were classified into four categories- High School, Diploma, Graduate and Post-graduation. For the ease of statistical analysis, they were regrouped into three groups, viz. 1-High School, 2- Diploma, 3-Graduate and Post-graduate. There were 25 participants with High school education, 5 with Diploma, 31 with Graduate degree/Post graduate degree. The results of descriptive statistical analysis are given in Table 4.5. The Kruskal-Wallis test was done to determine any significant difference between the FS-IS-K scores (subscale scores and total) across different levels of education. The chi-square values were found to be 3.44 (p=0.33), 2.26 (p=0.52), 0.25 (p=0.96) and 2.46 (p=0.48) with 2 degrees of freedom for subscale 1, subscale 2 and total scores (Table 4.5). The test results revealed no significant difference between the FS-IS-K scores across different levels of education.

Table 4.5

Mean, standard deviation (SD) and results of the Kruskal-Wallis test for the FS-IS-K scores across educational levels (N=60)

FS-IS-K	Mean (SD)			x^2	p-
	High School	Diploma	Graduate /Post graduate	(df=2)	value
Subscale 1	15.21(7.90)	9.6 (4.03)	15.90 (6.332)	3.45	0.33
Subscale 2	17.5 (10.87)	12.4 (3.28)	18.55 (8.35)	2.27	0.52
Subscale 3	13.96 (9.51)	9.80 (3.34)	12.77 (6.88)	0.25	0.97
Total Score	46.79 (26.46)	31.8 (10.37)	47.23 (19.06)	2.46	0.48

4.4.2 Care Recipient Related Variables

4.4.2.1 Comparison between the care recipient feeding dependency status and the FS-IS-K scores

The care recipients were divided into three groups, capable of self-care, capable of limited care and fully dependent. The care recipients who were completely able to perform self care independently were grouped under capable of selfcare (n=4). The care recipients who could take care of themselves to an extent but were dependent on their caregivers for certain needs including feeding were grouped under capable of limited self-care (n=24). The care recipients who were completely dependent on their caregivers for all their needs were grouped under fully dependent (n=32). The FS-IS-K scores were compared between the three categories of care recipient dependency, to see if there was an impact on the feeding-specific quality of life, especially when the child was dependent on the caregiver for feeding. Descriptive statistical analysis and Kruskal wallis test were performed. However, a slightly poorer quality of life was observed for fully dependent category among the three groups of dependency based on mean, even though it was not statistically significant.

The results obtained were suggestive of an overall decrease in the dysphagia-specific caregiver quality of life among caregivers caring for dependent care recipients depicting poorer QOL. This is indicated by an increase in the total scores of the Kannada version-FS-IS-K in the dependent group when compared to the independent group. The mean, standard deviation (SD) and results of the Kruskal-Wallis test for the FS-IS-K scores across care recipient dependency status are depicted in Table 4.6.

Table 4.6

Mean, standard deviation (SD) and results of the Kruskal-Wallis test for the FS-IS-K scores across care recipient dependency status (N=60).

FS-IS-K	Mean (SD)			x^2 (df=2)	p-value
	Capable of self-care	Capable of limited self-care	Fully Dependent		
Subscale 1	13.5 (9.60)	14.13 (5.84)	16.03 (7.52)	1.25	0.53
Subscale 2	12.25 (3.86)	15.29 (7.97)	20.03 (9.96)	4.47	0.10
Subscale 3	9.5 (4.12)	11.46 (6.62)	14.59 (8.75)	2.61	0.27
Total Score	35.25 (16.70)	40.88 (17.61)	50.75 (24.57)	3.21	0.20

4.4.2.2 Comparison between FS-IS-K scores and care recipient age

The total and subscale scores of the FS-IS-K tool were calculated for each care recipient and subjected to correlational analysis across their ages. Spearman's Rank Order correlational analysis was carried out. The results revealed that the correlation between the two variables was significant ($p<0.05$) across subscale 2, subscale 3 and total scores (Table 4.7). The correlation coefficient for subscale 1, subscale 2, subscale 3 and total scores were -0.15 ($p=0.26$), -0.36 ($p=0.05$), -0.31($p=0.02$) and -0.28 ($p=0.03$) respectively. The findings suggest that there was a weak negative correlation between the age of the care recipient and the feeding specific caregiver quality of life experienced by the caregiver based on the degree of correlation (Ali Abd Al-Hameed, 2022).There was a weak negative correlation between the effect of care recipient's age on the experienced difficulties in worry, feeding difficulties subscales as well as the total score. The results obtained were suggestive of an overall decrease in the feeding related quality of life of caregivers as the age of the care recipient increased. This is indicated by an increase in the total scores as well as two subscale scores of the FS-IS-K in the dependent group when compared to the independent group.

Table 4.7

Results of Spearman's Rank Order correlation between the care-recipient age and the FS-IS-K scores (N=60)

FS-IS-K	Correlation coefficient, r	p value
Subscale 1	-0.15	0.26
Subscale 2	-0.36	0.05
Subscale 3	-0.31	0.02
Total Score	-0.28	0.03

4.4.6 Comparison between gender of the care- recipient and the FS-IS-K Scores

The care recipients were divided into two groups-male and female. There were 38 males and 22 females. Descriptive statistical analysis was carried out along with the Mann-Whitney U test since the data followed a non-normal distribution. The results of the descriptive statistical analysis and Mann-Whitney U test have been presented in Table 4.8. The results of the Mann-Whitney U test revealed no statistically significant difference between the two groups, since the p-value was less than 0.05. The findings suggested that the gender of the care-recipients did not have a significant impact on the quality of life of caregivers.

Table 4.8

Mean, standard deviation (SD) and results of the Mann-Whitney U test for the FS-IS-K scores across different socioeconomic status (N=60)

FS-IS-K	Mean (SD)		/Z/	p-value
	Males	Females		
Subscale 1	14.87 (7.37)	15.50 (6.39)	0.44	0.66
Subscale 2	17.32 (9.12)	18.14 (9.58)	0.38	0.71
Subscale3	12.42 (7.95)	14.00 (7.70)	1.04	0.30
Total score	44.68 (22.03)	47.64 (22.27)	0.51	0.61

To summarize, the Kannada version of the Feeding and Swallowing Impact Scale (FS-IS-K) was found to be a reliable and valid tool for assessing the quality of life of caregivers of children with feeding deficits. It had excellent level of test-retest reliability and good internal consistency. There was a moderate positive correlation between FS-IS-K and the Kannada version of The Burden of Persons with Aphasia on the caregivers and a significant moderate positive correlation between FS-IS-K and FHI. The caregivers did have higher scores on the FS-IS-K scale, indicating a decrement in quality of life and increased burden. Greater concerns were expressed by caregivers in leaving the child with others for feeding, the family's difficulty in making plans or going out to eat, others' reactions to the child's feeding problem, worries about whether the child will ever eat and drink like typical children, and differing opinions from family members and professionals regarding feeding. In the current study, the variables contributing to the caregivers’ burden were identified as the care-recipient’s age. Other caregiver variables, such as age, education, socioeconomic status, and care recipient variables, such as gender, age of identification of feeding deficits were found to have no significant association with feeding-specific caregiver quality of life.

Chapter V

Discussion

This study is the first to characterise and quantify the quality of life of Kannada speaking caregivers with children who have feeding deficits secondary to cerebral palsy, through the development of a tool. Feeding difficulties can significantly impact both the child and the caregiver, causing emotional, physical, and social challenges. A few studies have reported that caregivers experience emotional stress, mealtime battles, financial strain, social isolation, thereby affecting family dynamics. The existing literature shows a higher prevalence of feeding and swallowing impairments in India (Pavithran et al., 2020). With the rising number of individuals facing these difficulties, there is a need for a tool specifically designed for the Indian context. This necessity arises from differences in family systems (nuclear/joint), population types (urban/rural), linguistic diversity, family dynamics, culture, food habits, and the varied educational and socioeconomic statuses in India compared to other countries. Currently, no standardized tool exists to assess and measure the feeding/swallow-related caregiver quality of life in any Indian language, including Kannada. Therefore, trans-adapting and validating the FS-IS (Feeding and Swallowing Impact Scale) in the Indian population was deemed essential, highlighting the need for replication.

The main objectives of the current study were to adapt, translate and validate the FS-IS screening tool to Kannada, which would help screen for feeding related caregiver quality of life of children. The other objectives were to identify any association between different caregiver or care recipient variables and the feeding-related quality of life of the caregiver.

The results of the current study identified the Kannada version of FS-IS (FS-IS-K) as a valid and reliable tool to screen for caregiver quality of life-specific to feeding difficulties among the primary caregivers of individuals with Cerebral Palsy. The results of the study are discussed in detail under different sections below.

5.1 Performance of the Primary Caregivers on the FS-IS-K

The results revealed that the primary caregivers of individuals with Cerebral Palsy experienced a decrement in quality of life as reflected to through the higher mean score on FS-IS-K. This is in agreement with the findings that primary caregivers of children with feeding deficits experience an increase in burden with changed roles, increased responsibilities and demands with respect to modified meal planning, preparation and feeding, occupational interferences, disrupted mealtime and socializations, fear of choking and aspiration etc. (McKee et al., 2008). Caregivers of children with CP face significant challenges, including time, economic pressures, and worries about choking or nutritional intake with higher concerns in the form of aspiratory risks and failure to thrive, in children who had severe impairments in swallowing (Lefton-Greif et al., 2014a; Serel Arslan et al., 2018a). According to Li et al., (2014), the lack of proper support and services during the management of dysphagia will affect the wellbeing and quality of life of the primary caregiver. Higher levels stress and worthless feeling are also reported in parents of children who exhibit aggressive behaviours only during mealtime interaction, than of parents whose children are diagnosed with feeding disorder due to a medical or a developmental etiology (Silverman et al., 2021b).

The impact on caregiver quality of life was measured using the Average Total Score (Lefton-Greif et al., 2014). The average total score represents the impact of feeding-related problems on the caregiver's quality of life. This was found to be 1.4 for the study that developed the English version of FS-IS (Lefton-Greif et al., 2014b), 2.63 for the study that developed the Turkish version of FS-IS(Serel Arslan et al., 2018a), 2.54 in the study that developed the South African version of FS-IS (Bestenbier et al., 2021), and 3.12 for the study that developed the Portugese-Barzilian version of FS-IS(Rama et al., 2022b). In the current study, the average score was found to be 2.54, which was similar to the value reported by Bestenbier et al., (2021). It was marginally greater than that reported by Lefton-Greif et al., (2014) and lower than those reported by the studies by Rama et al. (2022) and Serel Arslan et al. (2018). This discrepancy could likely be attributed to cultural, socio-economic, and methodological differences.

In Subscale 1 on daily activities, the highest percentage of participants affirmed difficulties in "leaving the child with others to feed them" and "difficulty for the family to make plans or go out to eat." Statements 1 and 2 followed closely, reflecting "difficulty managing a job or higher education" and "challenges in seeking help from others for feeding." These were the greatest areas of concern for the caregivers, which affected their day-to-day activities.

In Subscale 2 related to worry, the highest affirmative responses were for statements 8 and 10, which reported "caregiver’s worry about others' reactions to the child's feeding problem" and "worry that the child will never eat and drink like other children." They were concerned about whether they were doing enough to help their child with feeding. The studies by Lefton-Greif et al., (2014a) and Serel Arslan et al., (2018a) also reported that caregivers of children with CP worry about choking or nutritional intake with higher concerns in the form of aspiratory risks and failure to thrive, in children who had severe impairments in swallowing. The findings about the heightened concern for the child's general health align with those of other studies in the literature. The feeding difficulties not only affects the child's overall health and development but also significantly impacts the parent-child relationship, leading to considerable emotional distress for the caregivers (Budd et al., 1992). Child’s improved health from better caregiver feeding practices will reduce the time the mother spends caring for the child and decrease the amount of stress and anxiety. The present study in conjunction with previous studies affirms that caring for affected children led to time and economic challenges, as well as concerns about children choking, getting enough to eat, and the impact of these issues on other family members (Lefton-Greif et al., 2014; Redle, 2007).

In Subscale 3 on feeding difficulties, the highest response was for statement 17, which related to "difficulty feeding the child due to differing opinions from family members or professionals regarding the child’s feeding." The difference between expert opinion and family perspectives in medical contexts stems from disparities in knowledge, focus, emotional involvement, communication, cultural beliefs, and trust. Clinicians rely on scientific evidence and prioritize clinical outcomes, while families prioritize their loved one's perceived wishes and well-being, influenced by emotions and cultural values (Ho, 2009). This could have possibly lead to the increased responses to this statement.

A common observation noted while collecting data was that many caregivers felt embarrassed to give accurate scores as they believed that taking care of their child is their responsibility and should not be seen as something to complain about. Hence the scores given by the caregivers could be higher signifying poorer quality of life.

5.2 Establishment of Concurrent Validity of Trans-Adapted FS-IS-K Tool

A measure of a more general caregiver burden tool (Kannada version-‘ The Burden of Persons with Aphasia on the caregivers’) and an indirect indicator of dysphagia severity (Feeding Handicap Index) were used in the study. The feeding-specific caregiver quality of life, as measured by the FS-IS-K scores (Subscale 1, Subscale 2, Subscale 3 and Total scores), was positively associated to a moderate level with the FHI and with Kannada version-‘ The Burden of Persons with Aphasia on the caregivers’, indicating that poorer feeding -specific caregiver quality of life has an association with increased FHI level and increased general caregiver burden.

This association with FHI indicated that the better the oral intake of a child or the less restricted his/her diet is, better is the caregiver quality of life. That is, the effect of children's swallowing difficulties on their caregivers can vary depending on the severity of the dysphagia. As the severity of dysphagia in children increases, caregiver’s concerns also grow. Conversely, when the severity of dysphagia decreases, caregiver's concerns diminish. This was also reported in the studies by Lefton-Greif et al. (2014), Serel Arslan et al. (2018) and Rama et al. (2022). Polack et al. (2018) also reported that caregiver QoL was significantly lower among those caring for children with severe feeding difficulties. Previously other studies have reported that the severity and duration of child’s impairment has a positive correlation with caregiver stress (Carson & Schauer, 1992; Humphry & Rourk, 1991; Quittner et al., 1992)

5.3 Reliability of the Trans-Adapted FS-IS-K Tool

The reliability testing revealed a good internal consistency of 0.89 of the translated FS-IS-K tool across all the three subscales. The correlation coefficient for test-retest reliability measurement was found to be 0.99. The higher Cronbach’s alpha value indicate high reliability and good internal consistency of the Kannada version of FS-IS.

The internal consistency value of the present study is similar to the study on the development of the English version of FS-IS (Lefton-Greif et al., 2014), which was reported to be 0.89. In the other studies, the values for reliability were 0.99 (Serel Arslan et al., 2018) and 0.83 (Bestenbier et al., 2021, Rama et al., 2022), which were in agreement with the values found in the present study.

5.4 Influence of Variables on Feeding-related Caregiver Quality of Life

In the current study, the variables contributing to the caregiver quality of life were identified as the care recipient's age. Other caregiver variables, such as age, education, socioeconomic status, and care recipient variables, such as gender, age of identification of feeding deficits were found to have no significant association with feeding-specific caregiver quality of life. The discussion pertaining to caregiver and care recipient-related variables are provided in the subsections below.

5.4.1 Association between the trans-adapted FS-IS-K Tool and the caregiver and care recipient-related variables

Caregiver variables, such as age, education and socioeconomic status were found to have no significant association with the feeding-related caregiver quality of life in the current study. The finding that feeding-related caregiver quality of life was not dependent on the age of the caregiver is in consonance with a study done in caregivers of children with Foetal Alcohol Syndrome (Reid & Moritz, 2019).

The finding that education of the caregiver was not associated to caregiver quality of life is in agreement with a study conducted in caregivers of children with Atopic dermatitis (Olsson et al., 2020). However, in the study conducted to trans-adapt the original FS-IS to Brazilian-Portugese, there was a significant negative correlation between FS–IS scores and education (Serel Arslan et al., 2018).Two other studies done in adults with chronic health conditions also affirm the same results (Almeida-Brasil et al., 2017; Höfelmann et al., 2018). In a country like India, the high rate of illiteracy results in a limited number of highly qualified caregivers.40% of the participants in the study had only high school education. Hence the educational qualification of the caregivers were not evenly distributed. This discrepancy likely contributed to the differences in findings in the current study.

An association between feeding-related caregiver quality of life and different socio-economic categories were also not identified from the results of the current study. Most of the participants in the study were recruited from a central government institute that offers therapy services at a nominal cost. As a result, the majority of the participants recruited were from lower-income groups who lack the resources for higher education. Hence there was unequal distribution of participants in all the three socio economic categories. A study done in the caregiver burden of adults with dysphagia also found no significant difference between upper-lower and middle-class caregivers (Arakkal,2023).

However, several other studies found an association between socioeconomic status and quality of life. A study done in caregivers of children with Intellectual Disability reported that socioeconomic status of families is a crucial indicator of their overall well-being and happiness (Hu et al., 2012). Individuals with a low socioeconomic status may perceive a greater burden due to their likelihood of living in environments, lacking adequate facilities to meet patient needs. Patients in such conditions may have insufficient economic resources to obtain proper care and medication. Additionally, they may face difficulties such as lack of transportation, limited access to medical facilities, and a scarcity of social support organizations(Belasco & Sesso, 2002). Caregivers in these situations are more likely to experience financial constraints and have fewer options for seeking emotional or educational support. Low socioeconomic status has also been linked to depression in caregivers of patients with dementia (Schulz et al., 1995). The same finding is supported Greer et al., (2008). Thus the family socioeconomic status may be a source of stress for the primary caregiver, however our study was not able to confirm this, which could probably be because of the uneven participant distribution across the different socioeconomic classes.

An association between feeding-related caregiver quality of life and care-recipient age was identified from the results of the current study. There was a negative correlation between the effect of care recipient’s age on the experienced difficulties in worry, feeding difficulties subscales as well as the total score. The results obtained were suggestive of an overall decrease in the feeding related caregiver quality of life as the age of the care recipient increases. These findings are in consonance to a study conducted on caregivers of children with chronic diseases. This study confirms that the child's age at the time of diagnosis appears to moderate the chronic disease's impact on parental quality of life (PQL). Parents of younger children tend to report lower PQL (Goldbeck, 2006). Another study that evaluated parental stress on children with chronic illness also revealed that higher levels of parenting stress was associated with caring for young children (Streisand et al., 2001).

The study also found that care recipient’s dependency on caregivers for daily activities and self-care, such as feeding was not statistically significant. This again could be due to the uneven distribution of participants across the different dependency status. This result contradicts with the findings of other studies. For example, a study done in children with chronic diseases state that burden on caregivers increases as their child's level of dependency rises such as cerebral palsy or those affecting a child's mental status (Shattnawi et al., 2023). Likewise, another study reported that the level of burden among caregivers changes in accordance with the level of dependency of their chronically ill children, sometimes entirely dependent on them. A greater burden which had caused significant changes in behavior and functionality were observed in caregivers which was statistically significant(Arakkal, 2023). The increased burden on caregivers is likely due to their expanded responsibilities and the resulting time constraints, which hinder their ability to perform their own daily tasks and other necessary or preferred activities. This contributes to a heightened perception of poor feeding-specific caregiver quality of life. Individuals with intellectual disabilities (IWID) have illnesses characterized by a high level of dependency for selfcare, feeding and other needs. Caregivers often experience declining health and related issues due to role overload and physical fatigue associated with caregiving (Nam & Park, 2017).

The care recipient’s age of identification of feeding deficits was independent on the caregiver’s quality of life. This finding is supported by Greer et al., (2008). However, there are other studies in literature that emphasize the importance of early identification and intervention for feeding delays or disorders in children. There was a moderate to strong correlation between the total T-FS-IS score and the time to start oral feeding, indicating that earlier initiation of feeding is linked to fewer concerns. Early intervention is crucial as it can positively impact attachment and bonding between the child and caregiver, which can be affected from an early age. Early support is also essential for providing the necessary coping skills to parents and ensuring that feeding therapy starts at a young enough age to make a significant difference (Carpenter & Garfinkel, 2021). Comprehensive and early treatment of feeding problems in children with autism is crucial to prevent ongoing difficulties in the mother-child relationship that stem from early feeding failures, and to provide targeted therapy later on. Therefore, it is important to raise awareness among clinicians working with children with autism to systematically identify feeding problems at the earliest to reduce caregiver difficulties. This approach helps ensure timely intervention, preventing nutritional deficiencies and disorders in mother-child interactions (Cherif et al., 2018) Although it might be expected that earlier the identification of feeding deficit, lower the caregiver burden, our study was unable to confirm this. It is possible that the sample size was too small to detect differences between the participants who were identified early and late.

To sum, the Kannada version of the Feeding and Swallowing Impact Scale (FS-IS-K) has proven to be a reliable and valid tool for assessing the quality of life of caregivers of children with feeding difficulties in India.

Chapter VI

Summary and Conclusions

The quality of life of caregivers is often significantly impacted due to the physical, emotional, and financial demands of caregiving. Caregivers of children with disability experience physical exhaustion, stress, anxiety, and depression, which can lead to burnout. Their social lives may suffer due to isolation and strained relationships, and the economic burden can be substantial, especially, if caregiving affects their employment. Evaluating caregivers' quality of life helps identify their needs and challenges, enabling the provision of appropriate support and resources. This assessment also ensures that caregivers maintain their own health and well-being, which is crucial for sustaining the quality of care they provide. Moreover, understanding caregivers' experiences can help professionals plan intervention strategies, ultimately benefiting both caregivers and those they care for.

The quality of life of caregivers has been explored extensively in several different paediatric population (e.g., Cerebral Palsy, Autism Spectrum Disorder, Intellectual Disability and, Hearing impairment etc.) and tools to identify and measure caregiver quality of life are readily available and easily accessible worldwide. However, research specifically focused on the quality of life of caregivers dealing with feeding issues is limited, though it has gained more attention recently.

Feeding issues often coexist with many disabilities, acting as a comorbid condition. This means that children with various disabilities frequently experience feeding related difficulties. These challenges can stem from physical limitations, sensory sensitivities, or cognitive impairments, all of which can complicate proper feeding and diet management. Managing these challenges would require constant support from caregivers, which can be time-consuming and stressful, leading to emotional strain and fatigue. Caregivers may experience anxiety and frustration when trying to ensure their child receives adequate nutrition and maintains a healthy weight. These difficulties can also disrupt family routines and social activities, causing further stress.

The recent development of the FS-IS screening tool (Lefton-Greif et al., 2014) has paved the way for better understanding and addressing the quality of life and needs of caregivers of children with feeding deficits. The tool assists clinicians in identifying the sources and areas of difficulties faced by caregivers of children with feeding difficulties. In a multilingual country like India, where the number of children with feeding deficits and their caregivers are rising, there is a critical need for a similar quick, user-friendly, and straightforward tool to identify feeding-specific caregiver quality of life early. The unique aspects of India's family systems (nuclear/joint), urban and rural population distribution, linguistic diversity, cultural practices, food habits, and varied educational and socioeconomic statuses highlight the importance of adapting and validating the FS-IS tool in the Indian context.

Screening tools are preferred as primary evaluation methods due to their rapid, easy, and simple use, along with good internal consistency. The absence of a screening tool to evaluate feeding-related caregiver quality of life in the Indian context led to the adaptation, translation, and validation of FS-IS into Kannada. This study aimed to trans-adapt and validate the Feeding/Specific-Impact Survey (FS-IS), a tool developed by Lefton-Greif et al. (2014), which assesses the impact of feeding on caregivers and the associated caregiver quality of life across a wide age range and various paediatric conditions, into Kannada. The study aimed to achieve several objectives: to adapt and translate the Feeding/Specific-Impact Survey (FS-IS) into Kannada, to conduct content, clinical, and concurrent validation, to assess test-retest reliability, and to explore the relationship between various factors (such as caregiver age, socioeconomic status, caregiver education, care-recipient age and gender, age at which feeding deficits were identified, and feeding status) and the feeding-specific quality of life of caregivers.

The adaptation, translation, and validation of the current screening tool were conducted in four phases. The adaptation and translation was done following the standard WHO guidelines for the translation and adaptation of tools. The final version of the adapted screening tool incorporated all changes recommended throughout the process. The final Kannada version of FS-IS (FS-IS-K) is a tool consisting of 18 statements divided into three parts: Subscale 1 assesses the difficulties in daily activities encountered by caregivers over the last one month, while Subscale 2 evaluates the caregiver’s worry and Subscale 3 evaluates difficulties faced by the caregivers due to the child’s feeding difficulties.

This FS-IS-K was then administered on sixty primary caregivers of children with Cerebral Palsy in the age range of 2-18 years. This population was selected owing to the increased prevalence of feeding deficits in them and ease of availability. They were recruited from the Department of Clinical services and Preschool training center of AIISH and various other speech and hearing centres and special schools, in Mysuru, Karnataka, India. The children recruited for the study were enrolled for speech therapy, physiotherapy and/or special education in the concerned facilities. Primary caregivers aged 18 years and above and who were providing caregiving services for at least six months were recruited for the study. The caregivers were required to be able to read and understand Kannada. Primary caregivers with any other health issues or psychiatric illnesses were ruled out informally during the interview, and those who had prior experience in taking care of the needs of individuals with dysphagia were excluded from the study. The socioeconomic status of the participants was determined based on the modified Kuppuswamy socioeconomic scale (Sood & Bindra, 2022). A total of 60 participants (male:3, female:57) with a mean age of 34.63± 7.55 years completed the questionnaires.

The concurrent validity of the adapted tool was determined using 'The Burden of Persons with Aphasia on the caregivers' (Swati,2008). This scale offers a brisk screening and safe dependable method to recognise caregiver burden. This includes 40 questions and each question has a set of five choices from strongly agree to strongly disagree. Feeding Handicap Index (Shabnam & Swapna, 2023) was used to measure the severity of the feeding difficulties. FHI is a valid and reliable 38-item instrument. The responses of this tool was assessed on a 3-point Likert-type scale ranging from 0 to 3 (0: never has the problem, 1: sometimes has the problem 2: always has the problem). Test-retest reliability was carried out on 10% of the participants one week after the initial data collection.

The total, subscale and the average total scores of the FS-IS-K, scores of FHI and the Kannada version of The Burden of Persons with Aphasia on the caregivers ' and data on all other independent variables obtained were tabulated and entered into the SPSS software (version 26) for statistical analysis. Spearman's rho correlation coefficient was computed to determine the degree of association between FS-IS with FHI and test on The Burden of Persons with Aphasia on the caregivers. To assess the effect of different caregiver and care recipient variables on the feeding specific caregiver quality of life, each participant's total and subscale scores of the FS-IS-K were compared or correlated with the data obtained for these variables using appropriate statistical methods such as Kruskal-Wallis and Mann-Whitney U tests. The results revealed an average total score of 2.54, which indicated a decrement in caregiver quality of life. Greater concerns were expressed by caregivers in leaving the child with others for feeding, the family's difficulty in making plans or going out to eat, others' reactions to the child's feeding problem, worries about whether the child will ever eat and drink like typical children, and differing opinions from family members and professionals regarding feeding.

The trans-adapted tool was found to be statistically valid and reliable, with high test-retest reliability was 0.89 and good internal consistency of 0.99. There was an average (moderate) positive correlation between FS-IS-K and the Kannada version of The Burden of Persons with Aphasi on the caregivers and between FS-IS-K and FHI. The tool will assist clinicians in identifying the sources and areas of difficulties faced by caregivers of children with feeding difficulties. In the current study, the variable contributing to the caregivers' burden were identified as the care-recipient's age. Other caregiver variables, such as age, education, socioeconomic status, and care recipient variables, such as gender, age of identification of feeding deficits were found to have no significant association with feeding-specific caregiver quality of life. However, further study with a large sample size is required to confirm the findings because of the uneven and very limited number of participants in each category of the variables taken into consideration.

6.1 Clinical Implications

1. The adapted FS-IS-K tool provides healthcare professionals, especially dysphagia therapists, with valuable insights into the feeding-related quality of

life experienced by caregivers of children with Cerebral Palsy under 18 years with feeding deficits.

2. Practicing SLPs can also use the adapted FS-IS-K to assess and identify feeding-related caregiver quality of life in children with feeding deficits of any other aetiology in the Indian context.
3. This validated tool can offer insights into the sources and extent of the feeding-related quality of life experienced by caregivers.
4. The study identifies the most frequent and burdensome issues faced by caregivers in the Indian scenario during their caregiving journey.
5. Information obtained from the tool can guide clinicians in assembling the necessary healthcare specialist team (e.g., psychologist, social worker) and providing the support needed to address the problems of the caregivers. This includes offering education on feeding problems and its management, facilitating improved training, and delivering consistent support and resources.
6. Early identification of caregiver difficulties and their impact on quality of life using this screening tool can help develop organized, effective, and impactful tailor-made intervention strategies that involve the entire family unit, along with the patient and primary caregivers. This approach can enhance the quality of life for caregivers and their care recipients, particularly within the Kannada-speaking population.
7. The tool can also be used to evaluate the effectiveness of a treatment plan by comparing pre- and post-treatment FS-IS-K scores.

6.2 Limitations

The limited sample size in the undertaken study does not facilitate the assessment of the interaction effect of variables on the feeding-related caregiver quality of life. Several potential variables like family type, family size, duration of feeding intervention, occupation of the caregiver, presence of multiple caregivers and /or care recipients, caregiver's relationship with other family members, sibling order, cognitive status of the care recipient, other medical conditions etc. which might contribute to the caregiver quality of life could not be analysed due to decreased statistical number. The study lacks all the possible socio-economic status groups, as well as the limited number of participants who are highly qualified, which could affect the generalization of the results.

India has an illiteracy rate of 26% (Dakshesh et al., 2023). In the state of Karnataka, the illiteracy rate is higher, with 67.04% in rural areas and 81.05% in urban areas (Ravi, n.d.). Due to the self-administered nature of the current tool, caregivers from illiterate backgrounds found it challenging to respond to the test items/statements in FS-IS-K. Considering India's diverse and multilingual population, creating different language versions of FS-IS and then validating it clinically would be impractical. Therefore, a need was felt necessary to develop a clinician-administered version of FS-IS. Consequently, the translated tool was adapted to a clinician-administered format, tailored to Indianized English. The clinician administered English version would facilitate its administration on a larger population hailing from different linguistic backgrounds, provided the clinician also knows that language. Considering that India is a multilingual country, with each individual having a spoken proficiency in atleast two to three languages, the English version of the tool will find a larger utility. However, this needs to be content and clinically validated on a larger multilingual population (Appendix IV).

6.3 Future Directions

1. The sample size could be increased and diversified to ensure adequate representation for each variable considered, and the interaction effects between variables could be analyzed.
2. A cut-off score could be established to categorize the burden into different severity levels.
3. The sensitivity and specificity of the translated tool could be determined.

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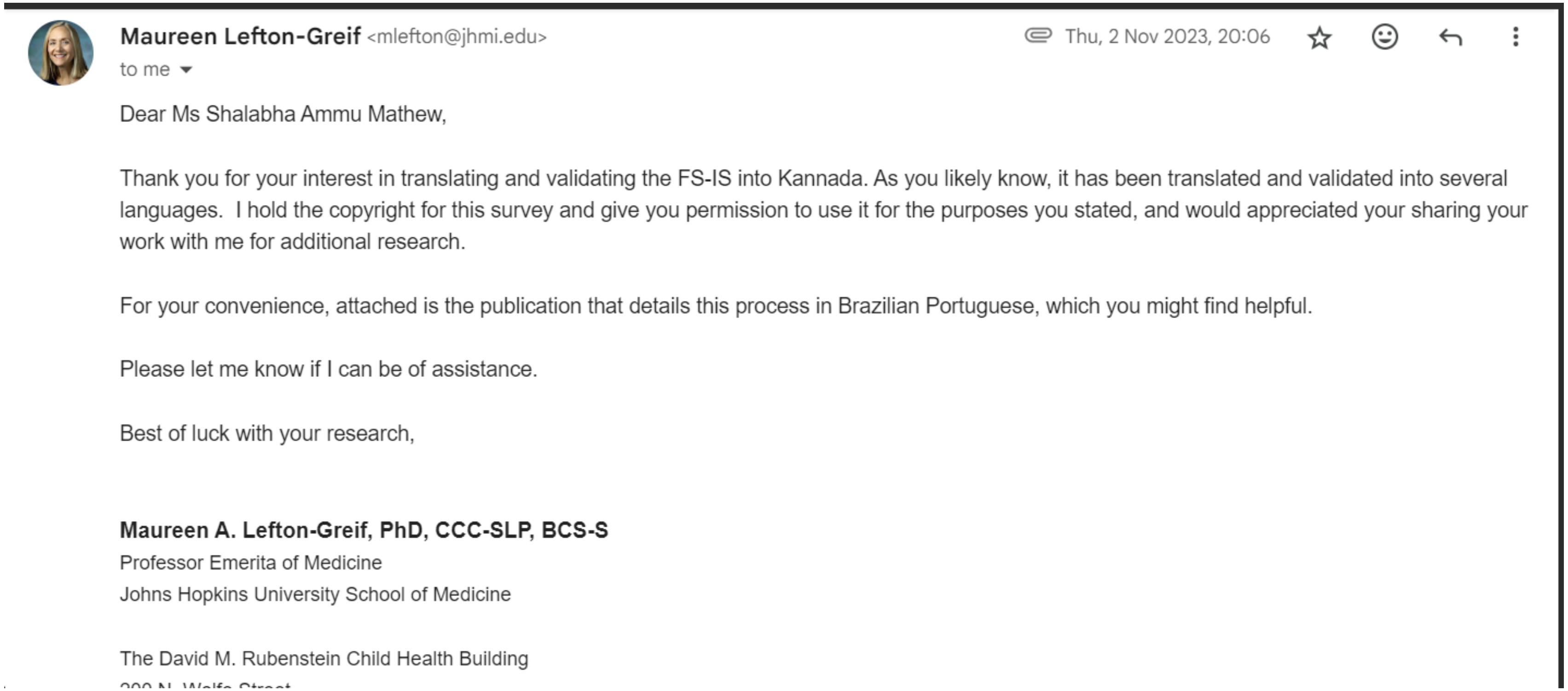
Appendix I

Consent From Author



Maureen Lefton-Greif <mlefton@jhmi.edu>

to me

Thu, 2 Nov 2023, 20:06

Dear Ms Shalabha Ammu Mathew,

Thank you for your interest in translating and validating the FS-IS into Kannada. As you likely know, it has been translated and validated into several languages. I hold the copyright for this survey and give you permission to use it for the purposes you stated, and would appreciated your sharing your work with me for additional research.

For your convenience, attached is the publication that details this process in Brazilian Portuguese, which you might find helpful.

Please let me know if I can be of assistance.

Best of luck with your research,

Maureen A. Lefton-Greif, PhD, CCC-SLP, BCS-S
Professor Emerita of Medicine
Johns Hopkins University School of Medicine

The David M. Rubenstein Child Health Building
200 N. Wolfe Street

Appendix II

Feeding/Swallow-Impairment Scale-Kannada (FS-IS-K) (in IPA)

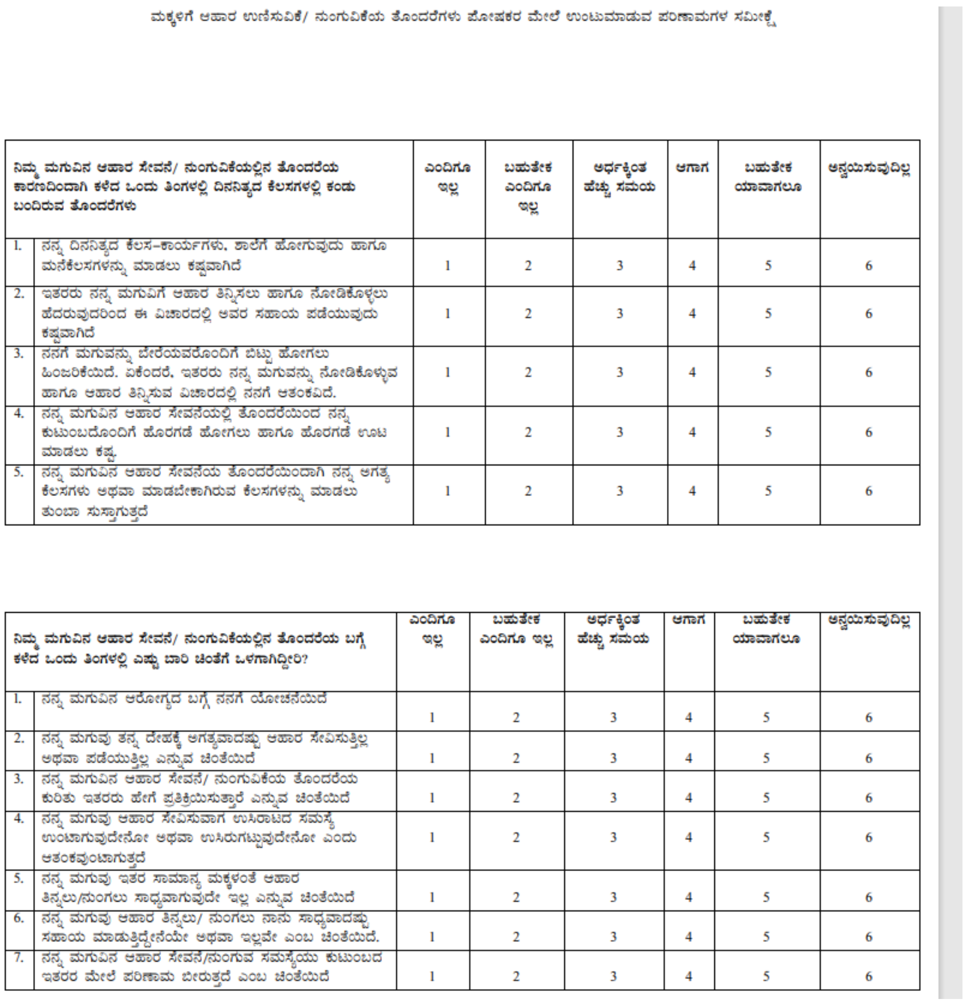
makkaɭige a:ha:ra unisuvike/ nunguvikəja tondaregaɭu poʃaka:ra məle untuma:duvɑ parina:ma samIkʃe

nımmɑ mæguvınɑ a:ha:ra səvane/nuguvıkəyaɭina tondarəya ka:raŋadinda:gi kaleda ondu tingɑɭɑɭi dinanithyada kelasagalaɭi kandu bandiruvɑ tondaregaɭu	**əndigu illa (1)**	**bahutəka endigu illa (2)**	**ardhakkinta heku samaja (3)**	**aga:ga (4)**	**bahutəka ja:vagaɭu (5)**	**Anvajisuvudila (6)**
1. nanna dinanıtʰyɑda keɭasa-ka:ryagaɭu, sha:lege hoguvudu ha:gu manekelasagaɭannu ma:dalu kaʃtavagide						
2. Itararu nannɑ maguvIgə a:ha:ra thinnisaɭu ha:gu nodikoɭɑlu hədɑruvudarinda ee vichaaradalli avara saha:ya padəyuvudu kaʃtava:gıdə						
3. nanəge maguvannu bərəyavaroɚndige bittu hogalu hingarikeide. Ekendare, itararu nanna maguvannu nodikoɭuva hagu a:ha:ra tinnIsuva vichæradaɭi nanage atankavide.						
4. nanna maguvIna a:aara səvanejaɭi tondərejindɑ nanna kuttumbadondIge horagade hogalu haagə horagade o:ta maadalu kaʃta.						
5. nanna maguvina a:ha:ra səvaneya tondareyinda:gi agatja tumba susta:guttade.						

Nımmɑ mæguvınɑ a:ha:ra səvane/nuguvıkəyaɭina tondarəya ka:raŋadinda:gi kaleda ondu tingɑɭɑɭi dinanithyada kelasagalaɭi kandu bandiruvɑ tondaregaɭu	**əndigu illa**	**bahutəka endigu illa**	**ardhakkinta heku samaja**	**Aga:ga**	**bahutəka ja:vagaɭu**	**anvajisuvudila**
1. nanna maguvinɑ arogjadɑ bagə nænagə jochanejide						
2. nanna maguvu tanna dəhəkke agatjava:daʃtu a:ha:ra səvisuttila athava padejuttila enuva chintæde						
3. nanna maguvina a:ha:ra səvane/nunguvikəja tondareja kuritu itararu hægə pratikrijisutta:re ennuva chinteide						
4. nanna maguvu a:haara səvisuva:ga usira:tada samasye unta:guvudəno athavɑ usirugattuvudəno endu atankavunta:guttade						
5. nanna maguvu itara sa:mɑnya makkaɭante a:ha:ra tinnaɭu/nungaɭu sa:djava:guvude iɭa ennuva chintædə						
6. nanna maguvu a:haara tinnalu/nungalu naanu sa:dhjava:daʃtu saha:ja ma:dutidənejə ɑthava illavə emba chintæde.						
7. nanna maguvIna a:ha:ra sevane/nunguva samasyeyu kutumbada itarara məle parina:mɑ bIruttadə emba chintæde						

Nımmɑ mæguvınɑ a:ha:ra səvane/nuguvıkəyaɭina tondarəya ka:raŋadinda:gi kaleda ondu tingɑɭɑɭi dinanithyada kelasagalaɭi kandu bandiruvɑ tondaregaɭu	**əndigu illa**	**bahutəka endigu illa**	**ardhakkinta heku samaja**	**Aga:ga**	**bahutəka ja:vagaɭu**	**Anvajisuvudila**
1. nunguva sa:marTjəkke thakkante dravaha:ra mattu ithara a:ha:ravannu thajarisalu hechu samaya thegeduɭuvudarinda maguvige sariyagi thinnisaɭu agutila						
2. maguvige agathjavaagiruva dravapadaartha ha:gu itare a:ha:ravannu thaya:risalu nanage thiɭidilladiruvudarinda maguvige a:ha:ra niduvudu kaʃtava:gidə						
3. itharaRu nanna maguvige sukthavalada dravapadartha hagu ithare a:haaravannu nIduvudarinda maguvige a:ha:ra thinisuvudu kaʃtava:gide						
4. nanna maguvina a:ha:ra səvene/nunguvikeja samasyegaɭu eɭiyavarəgə iruttavə embudu tiɭidilava:ddarinda a:ha:ra thinnisuvudu kaʃtava:gidə						
5. maguvige a:ha:ra unisuva tondaregaɭa bagə manejavaru mathu vruttipɑraru vibhina abhipra:ya/salahegaɭu nIdiruvudarinda maguvige a:ha:ra thinnisalu kaʃtavagide.						
6. itara makkaɭante nanna maguvu saha a:ha:ra səvisuvantə maduva bage nanage sariyaada maahithi illada karana maguvige a:ha:ra thinnisuvudu kaʃta						

Feeding/Swallow-Impairment Scale-Kannada (FS-IS-K)



ಮಕ್ಕಳಿಗೆ ಆಹಾರ ಉಣಿಸುವಿಕೆ/ ನುಂಗುವಿಕೆಯ ತೊಂದರೆಗಳು ಪೋಷಕರ ಮೇಲೆ ಉಂಟುಮಾಡುವ ಪರಿಣಾಮಗಳ ಸಮೀಕ್ಷೆ

	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

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 ಮಯ 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 ವೃತ್ತಿಪರರು 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

Appendix-III

Feeding/Swallow-Impairment Scale- English

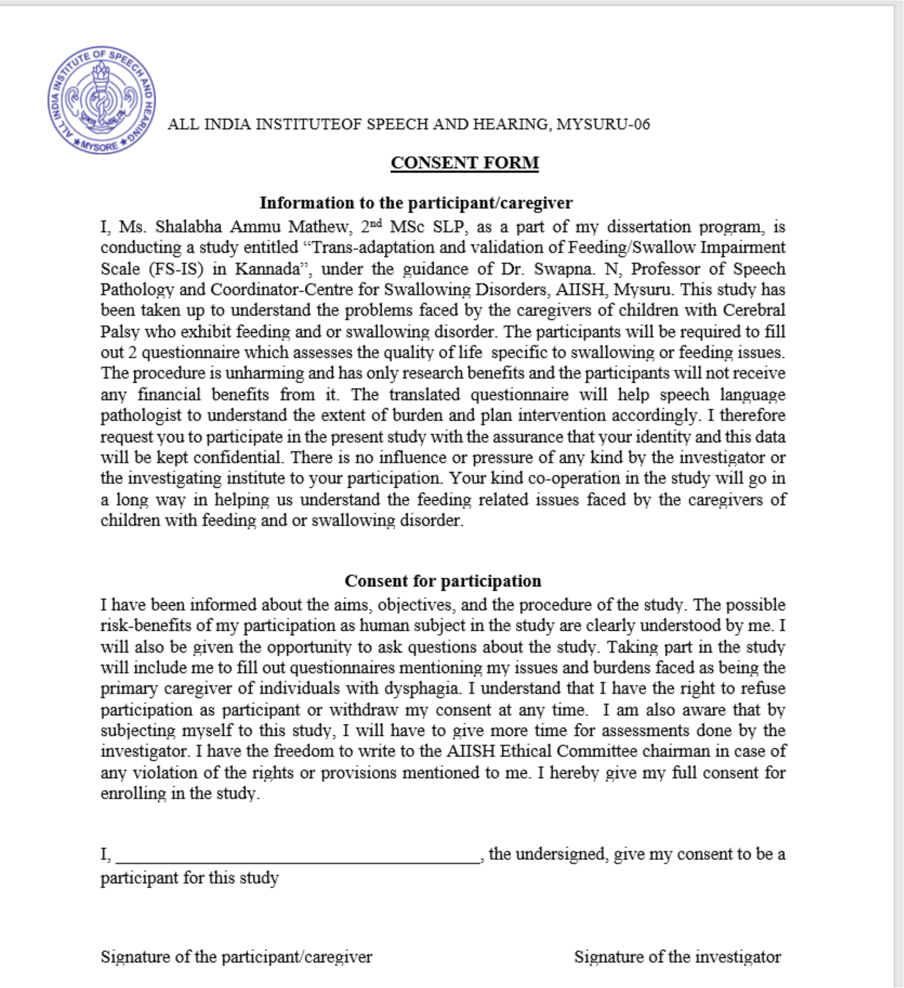
In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **<u>you</u>** had problems **carrying out your daily activities?**		**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	It is hard for me to do my job, go to school, or work around the house.	1	2	3	4	5	6
2	It is hard for me to get help from others because they are scared to feed or take care of my child.	1	2	3	4	5	6
3	It is hard for me to leave my child because I am scared to have other people feed or take care of my child.	1	2	3	4	5	6
4	It is hard for my family to make plans or go out to eat.	1	2	3	4	5	6
5	I am too tired to do the things I want or need to do.	1	2	3	4	5	6

In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems with **worrying?**		**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	I worry about my child's general health.	1	2	3	4	5	6
2	I worry that my child does not get enough to eat or drink.	1	2	3	4	5	6
3	I worry about how others will react to my child's feeding/swallowing problems.	1	2	3	4	5	6
4	I worry about how my child breathes when feeding and whether my child will choke.	1	2	3	4	5	6
5	I worry that my child will never eat and drink like other children.	1	2	3	4	5	6
6	I worry about whether I am doing enough to help with my child's feeding /swallowing problems	1	2	3	4	5	6
7	I worry about how my child's feeding/swallowing problems affect others in my family.	1	2	3	4	5	6

In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems **carrying out your daily activities?**		**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	It is hard for me to do my job, go to school, or work around the house.	1	2	3	4	5	6
2	It is hard for me to get help from others because they are scared to feed or take care of my child.	1	2	3	4	5	6
3	It is hard for me to leave my child because I am scared to have other people feed or take care of my child.	1	2	3	4	5	6
4	It is hard for my family to make plans or go out to eat.	1	2	3	4	5	6
5	I am too tired to do the things I want or need to do.	1	2	3	4	5	6

Appendix IV

Consent Form



ALL INDIA INSTITUTEOF SPEECH AND HEARING, MYSURU-06

CONSENT FORM

Information to the participant/caregiver

I, Ms. Shalabha Ammu Mathew, 2nd MSc SLP, as a part of my dissertation program, is conducting a study entitled "Trans-adaptation and validation of Feeding/Swallow Impairment Scale (FS-IS) in Kannada", under the guidance of Dr. Swapna. N, Professor of Speech Pathology and Coordinator-Centre for Swallowing Disorders, AIISH, Mysuru. This study has been taken up to understand the problems faced by the caregivers of children with Cerebral Palsy who exhibit feeding and or swallowing disorder. The participants will be required to fill out 2 questionnaire which assesses the quality of life specific to swallowing or feeding issues. The procedure is unharming and has only research benefits and the participants will not receive any financial benefits from it. The translated questionnaire will help speech language pathologist to understand the extent of burden and plan intervention accordingly. I therefore request you to participate in the present study with the assurance that your identity and this data will be kept confidential. There is no influence or pressure of any kind by the investigator or the investigating institute to your participation. Your kind co-operation in the study will go in a long way in helping us understand the feeding related issues faced by the caregivers of children with feeding and or swallowing disorder.

Consent for participation

I have been informed about the aims, objectives, and the procedure of the study. The possible risk-benefits of my participation as human subject in the study are clearly understood by me. I will also be given the opportunity to ask questions about the study. Taking part in the study will include me to fill out questionnaires mentioning my issues and burdens faced as being the primary caregiver of individuals with dysphagia. I understand that I have the right to refuse participation as participant or withdraw my consent at any time. I am also aware that by subjecting myself to this study, I will have to give more time for assessments done by the investigator. I have the freedom to write to the AIISH Ethical Committee chairman in case of any violation of the rights or provisions mentioned to me. I hereby give my full consent for enrolling in the study.

I, ____, the undersigned, give my consent to be a participant for this study

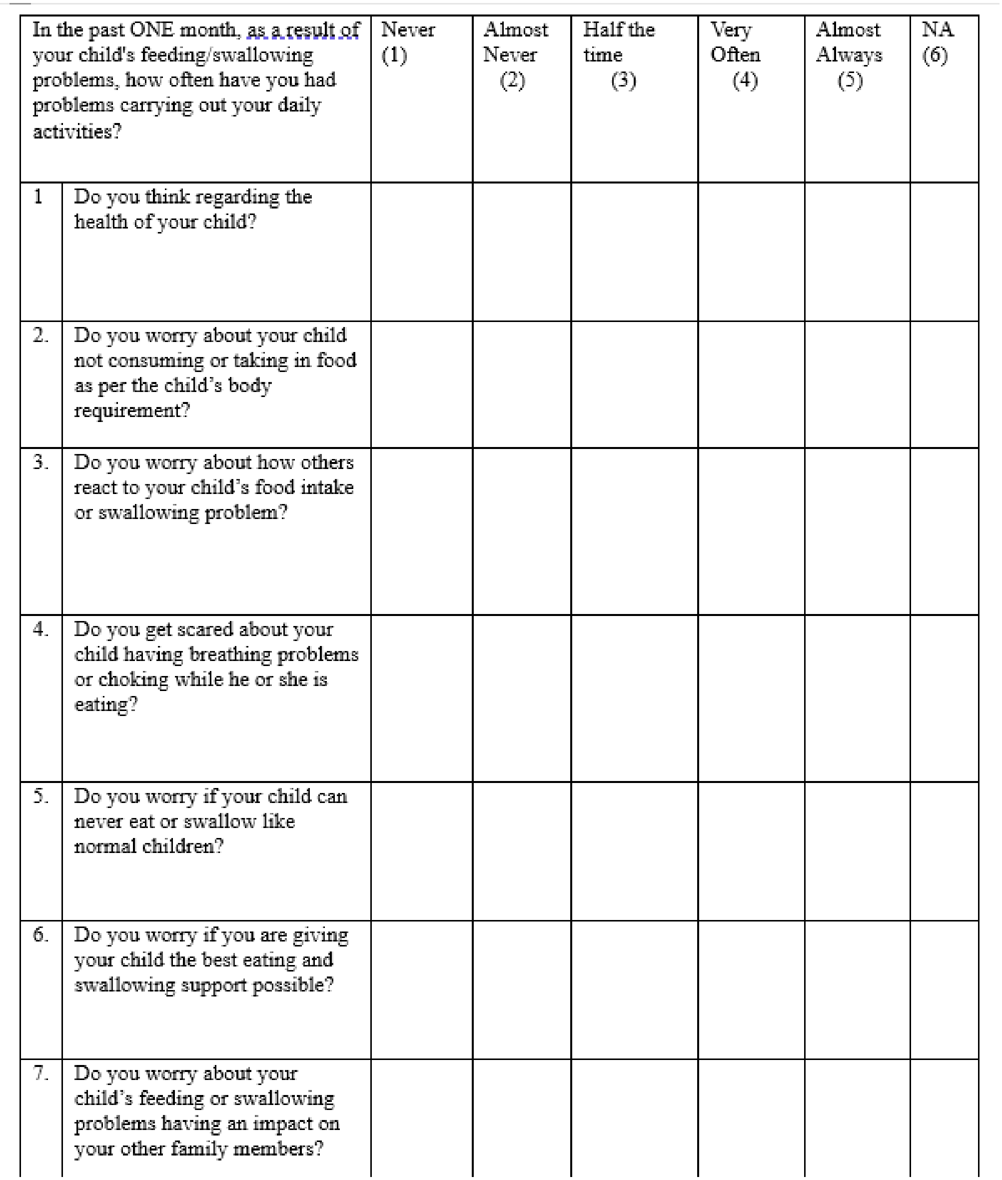
Signature of the participant/caregiver Signature of the investigator

Appendix V

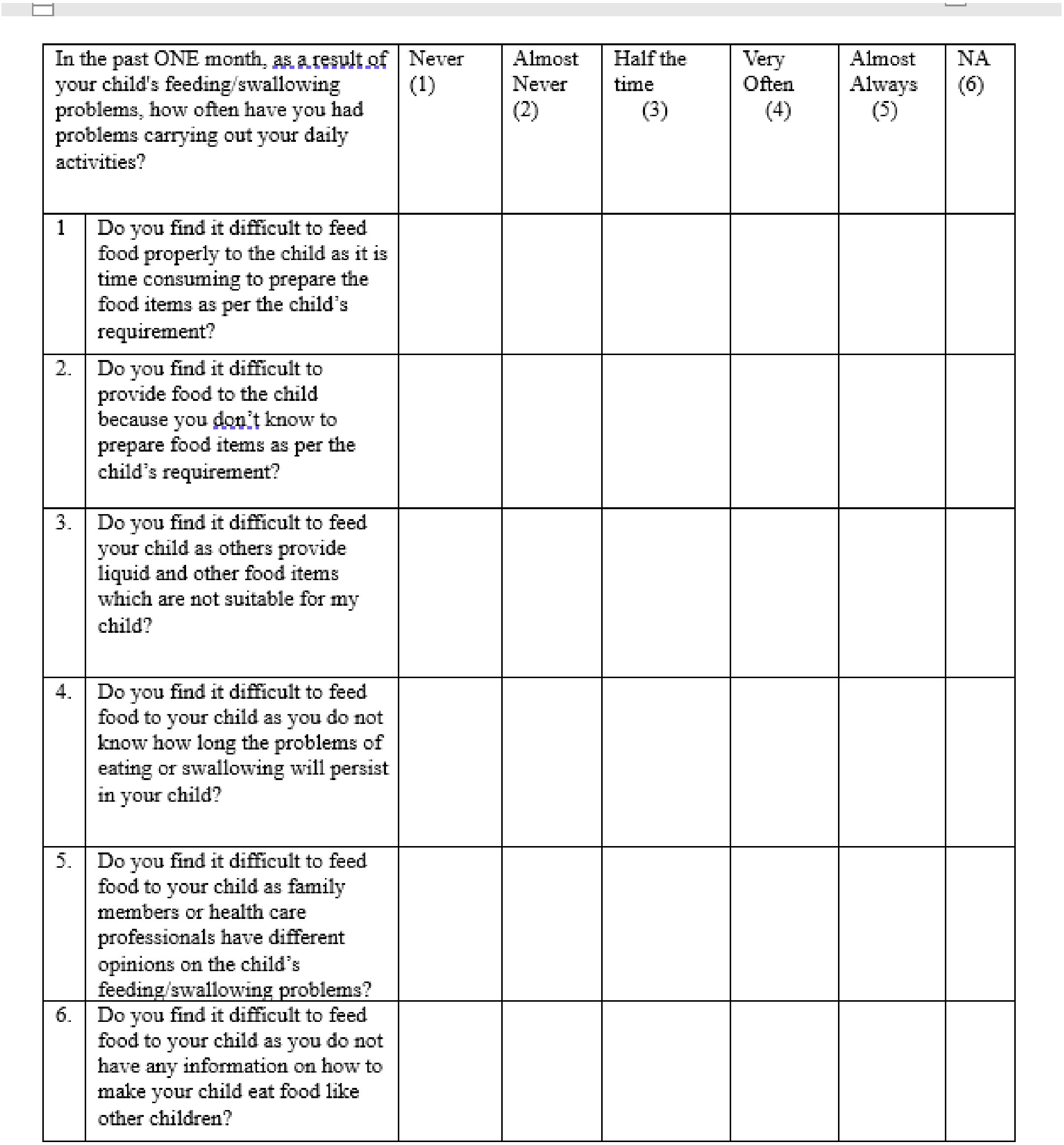
Feeding/Swallow- Impairment Scale- English (adapted to Indian scenario)

Feeding/Swallow-Impairment Scale Adapted English

In the past ONE month, as a result of your child's feeding/swallowing problems, how often have you had problems carrying out your daily activities?		Never (1)	Almost Never (2)	Half the time (3)	Very Often (4)	Almost Always (5)	NA (6)
1	Do you find it difficult in carrying out routine activities, going for higher studies and doing household work?						
2.	Do you find it difficult to take the help of others as they are afraid to feed and look after your child?						
3.	Do you feel reluctant or scared to leave your child with others in the matter of them looking after your child and feeding food to your child?						
4.	Do you find it difficult to go out and have food outside with your family as your child has feeding issues or problem in food consumption?						
5.	Do you find it tiring to do your essential work and other routine work because of the feeding problems of your child?						



In the past ONE month, as a result of your child's feeding/swallowing problems, how often have you had problems carrying out your daily activities?		Never (1)	Almost Never (2)	Half the time (3)	Very Often (4)	Almost Always (5)	NA (6)
1	Do you think regarding the health of your child?						
2.	Do you worry about your child not consuming or taking in food as per the child’s body requirement?						
3.	Do you worry about how others react to your child’s food intake or swallowing problem?						
4.	Do you get scared about your child having breathing problems or choking while he or she is eating?						
5.	Do you worry if your child can never eat or swallow like normal children?						
6.	Do you worry if you are giving your child the best eating and swallowing support possible?						
7.	Do you worry about your child’s feeding or swallowing problems having an impact on your other family members?						



In the past ONE month, as a result of your child's feeding/swallowing problems, how often have you had problems carrying out your daily activities?		Never (1)	Almost Never (2)	Half the time (3)	Very Often (4)	Almost Always (5)	NA (6)
1	Do you find it difficult to feed food properly to the child as it is time consuming to prepare the food items as per the child's requirement?						
2.	Do you find it difficult to provide food to the child because you don't know to prepare food items as per the child's requirement?						
3.	Do you find it difficult to feed your child as others provide liquid and other food items which are not suitable for my child?						
4.	Do you find it difficult to feed food to your child as you do not know how long the problems of eating or swallowing will persist in your child?						
5.	Do you find it difficult to feed food to your child as family members or health care professionals have different opinions on the child's feeding/swallowing problems?						
6.	Do you find it difficult to feed food to your child as you do not have any information on how to make your child eat food like other children?						