TRANS-ADAPTATION AND VALIDATION OF CAREGIVER ANALYSIS OF REPORTED EXPERIENCES WITH SWALLOWING DISORDERS (CARES) SCREENING TOOL IN MALAYALAM

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September 2023

CERTIFICATE

This is to certify that this dissertation entitled **“Trans-Adaptation and Validation of Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) Screening Tool in Malayalam”** is a bonafide work submitted in part fulfillment for the degree of Masters in Science (Speech-Language Pathology) of the student Registration number P01II21S0026. 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 an award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled **“Trans-Adaptation and Validation of Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) Screening Tool in Malayalam”** is the result of my own study under the guidance of Dr. Swapna N, Head of Department of Clinical Services and Coordinator of Center for Swallowing Disorders, All India Institute of Speech and Hearing, Mysuru, and has not been submitted earlier to any other University for award of any other Diploma or Degree.

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Chapter I

Introduction

Dysphagia is a debilitating condition with extensive consequences ranging from malnutrition to mortality in extreme cases (Altman et al., 2010; Cartmill et al., 2012; Crary et al., 2012; Gupta et al., 2022; Jones et al., 2018; Namasivayam-MacDonald et al., 2017; Nguyen et al., 2006; Shune et al., 2012; van den Berg et al., 2014). Dysphagia pertains to any swallowing impairment involving difficulty in moving ingested material (liquid and food) and/or secretions (e.g., saliva) from the mouth to the stomach, resulting in an increased likelihood for poor nutritional outcomes (malnutrition, dehydration) and/or threat to airway protection (choking, penetration, aspiration). Dysphagia is an associated outcome of stroke, head and neck cancer, neurodegenerative disorders, dementia, and brain injury (Shune & Namasivayam-MacDonald, 2019, 2020). Further, certain congenital anomalies, structural changes, and/or medical conditions sometimes result in dysphagia. Illnesses and disorders associated with dysphagia can reach beyond health measures, changing patients' daily living and mealtime habits, negatively impacting their social life and overall quality of life, escalating their feelings of anxiety and despair and increasing mortality (Karvonen-Gutierrez et al., 2008; Klinke et al., 2013; Namasivayam-MacDonald & Shune, 2018; Nguyen et al., 2005).

Along with the individuals experiencing dysphagia, these outcomes majorly affect their caregivers (spouses, children, parents, etc.), other family members, relatives, and friends. Caregivers assist individuals with dysphagia with their daily routines in reducing associated biopsychosocial impact and in promoting an improved quality of life, including meal planning, meal preparation, feeding, nutrition and safety monitoring, and delivering emotional and social support (Mayre-Chilton et al., 2011; Nund et al., 2014; Patterson et al., 2012). Changes in roles and responsibilities, shifts in daily routines and increased schedule rigidity in caregivers' lives often negatively impact family dynamics. Difficulties with food and mealtimes stemming from dysphagia impede interpersonal interactions and social connections, thus disrupting the whole family's psychosocial well-being, particularly the primary caregivers. Regardless of the care recipients' condition, the caregivers' age, the relationship between the care recipient and their caregiver, caregivers experience dysphagia-related caregiving burdens such as disruption in lifestyle and social life, modifications in meal preparation, handling of feeding tubes, lack of support, and fear of aspiration (Rangira et al., 2022).

Caregiver burden refers to the overall load and strain experienced by an individual as a consequence of caring for another individual, either a family member, a relative or a friend, aka informal caregiving, and these consequences arise from the needs and demands of the individual with a medical/neurological condition (Shune & Namasivayam-MacDonald, 2020).

The caregivers report experiencing an overload of responsibility and increased feelings of stress, anxiety, depression, frustration, despair, fear, worry/concern, sympathy, anger, helplessness, guilt, seclusion, and overall decreased quality of life associated with increased domestic responsibilities, widespread activity limitations and participation restrictions and care recipient's meal preparation, aspiration and choking, and significant weight loss (de Wit et al., 2017; Johansson & Johansson, 2009; Kumar et al., 2022; Lisiecka et al., 2020; Namasivayam-MacDonald & Shune, 2019; Nund et al., 2014, 2016; Patterson et al., 2012; Penner et al., 2012; Arslan et al., 2017; Shune & Namasivayam-MacDonald, 2019, 2020; Zimmerman et al., 2022).

Thus, dysphagia is not limited to a single individual but brings a psychosocial strain on the entire family (Rolland, 2019). Caregivers face increased financial, psychological, social, and time commitment demands to meet needs and demands specific to dysphagia, along with an increase in their responsibilities and changes in daily living (Howells et al., 2020; Namasivayam-MacDonald & Shune, 2019, 2020; Pérez et al., 2022; Arslan et al., 2017).

Frequently, in-home caregiving services and other healthcare-related activities consume up to 28 hours of a caregiver per week with no compensation (Gibson & Houser, 2007; Wolff et al., 2016). The inability to preserve a full-time, paid occupation often leads to financial burdens. The high expenditure associated with caregiving impacts caregivers' daily functioning, physical and psychosocial health, and well-being (Coutts & Solomon, 2020; Kumar et al., 2022; Schulz & Sherwood, 2008). The financial burden also leads to a high probability of associated problems, such as emotional struggle (e.g., depression, distress, frustration, anxiety, and fatigue), reduced overall immunity, and diminished quality of life across physical, emotional, and psychosocial domains (Allen et al., 2017; Dawood, 2016; de Wit et al., 2017; Jacob et al., 2020; Kiecolt-Glaser et al., 1991; Liu et al., 2017; Schulz et al., 1995, 1997). The reduced health and well-being of the caregivers results in providing less quality care services. Consequently, a negative impact on the care recipient's health (worsened physical, behavioural, psychological and functional health outcomes; increased risk of institutionalization; and reduced quality of life) is evident (Bilotta et al., 2010; Stall et al., 2018). This demands greater care for the recipient (Torti et al., 2004; Wolff et al., 2016). Hence, such profound "third-party disability", or impaired functioning and ability of significant others or family members originating from the health condition of an individual (Nund et al., 2014, 2016; *World Health Organization (WHO). International Classification of Functioning, Disability* *and Health, ICF. Geneva: World Health Organization, 2001.*, n.d.), signifies the need to consider family members both as a part of a patient's aid strategy and as individuals with self-requirements.

Several studies extensively enunciate caregiver burden in different populations, yet studies related to dysphagia-specific caregiver burden have not been focused on until recent years. Previous studies on caregivers of individuals with dysphagia associated with several conditions (e.g., stroke, aphasia, dementia, cancer, neurodegenerative diseases, psychiatric disorders) indicate that people in close proximity with individuals with dysphagia suffer fromcaregiving burden and reduced quality of life as a consequence of their long-term services (Johansson & Johansson, 2009; Miller et al., 2006; Namasivayam-MacDonald & Shune, 2018, 2020b; Nund et al., 2014, 2016; Patterson et al., 2012; Penner et al., 2012; Shune & Namasivayam-MacDonald, 2020b; Zimmerman et al., 2022). A study done on caregivers of individuals with Parkinson's disease suggests that the combined effect of increased age and duration of the condition resulted in reduced caregiver quality of life (Perry et al., 2022). Previous studies report increased burden, stress and anxiety in caregivers managing tube feedings as they feel inadequately proficient in managing the same, increasing the risk of tube feeding complications (Namasivayam-MacDonald & Shune,2018; Penner et al., 2012). Another study also reports that the care recipients dependent on food texture modification significantly increased the caregiver burden compared to those dependent on tube feeding, suggesting that the caregiver burden varies depending on the care recipients' oral intake status (Suzuki et al., 2022).

Several caregiver burden assessment tools such as the Care-giving Burden Scale (CBS) (Gerritsen & van der Ende, 1994), the Zarit Burden Interview (ZBI; Zarit et al., 1980, 1986), the Family Burden Interview Schedule (Pai & Kapur, 1981), the Caregiver Burden Inventory (Novak & Guest, 1989), the Modified Caregiver Strain Index (Thornton & Travis, 2003), the Caregiver Burden Scale (CBS; Elmståhl et al., 1996), the Caregiver Self-Assessment Questionnaire (Epstein-Lubowet al., 2010), Caregiver Burden Scale-Indian Population (Pandey et al., 2019), Malayalam version - Caregiver Burden Assessment Scale (Arsha, 2020) etc., are available to recognize general feelings of burden and pressure. Another tool, titled The Burden of Persons with Aphasia on the Caregivers (Swati, 2008), developed in the Indian context, assesses the burden on caregivers specifically due to communication difficulties of individuals with Aphasia. However, these do not address dysphagia-specific burden. These tools include role upgradation, schedule overload, competence, personal gain, relationship disruption, coping, family beliefs and conflict, occupational conflicts, and financial issues-based items.

Specific to dysphagia, a tool was developed by Jain and Jagtap (2021) in Marathi, which evaluates the quality of life of caregivers delivering care services to people with dysphagia. The Marathi questionnaire was created using the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ) and the International Classification of Function and Disability (ICF) codes as references. The tool has three sections with 42 statements or questions divided among the three sections, namely, "activities of daily living and social (ADLS)", "feelings and attitudes (FA)", and "feeding". The 14 statements in the ALDS section evaluate how dysphagia affects the carers' ability to participate in social activities, engage in leisure activities, work, and manage their finances, along with changes that happened during mealtimes. The 12 statements in the FA section examine how the caregiver feels about dysphagia and the worries it causes. The final section has 16 feeding-related statements, six of which were universal for caregivers feeding their patients and five of which were exclusive to oral and tube feeders, respectively. Though this tool has been in the Indian context and touches upon aspects of caregiver burden, the focus is broader, comprising of the assessment of quality of life, is elaborate and is in the Marathi language. There is a specific need for a quick, short and simple screening tool to identify caregiver burden.

Keeping this in view, one screening tool developed recently is the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) by Shune and Namasivayam-MacDonald (2020). This assesses the impact of dysphagia on a caregiver and the associated caregiver burden across a wider age group and across several etiologies that lead to dysphagia (Shune et al., 2020). The CARES questionnaire consists of 26 statements specific to dysphagia-related caregiver burden, classified under two subscales, along with two other sections under each subscale to highlight the most burdensome among these statements. The Part A subscale, containing ten statements, assesses for the behavioral and functional changes in the caregiver, while Part B, containing 16 statements, assesses for the subjective caregiver stress. The caregivers have to indicate either 'Yes' or 'No' for each statement or 'Not applicable (N/A)' if the statement describing the situation or the caregiver's stress has not occurred. A score of 1 is given for each 'Yes' response. A higher score suggests a more significant perceived burden of care by the caregivers. An additional question is included at the bottom of each subscale to elicit information regarding the statements that are most burdensome. Also, specific to assessing caregiver issues in the area of dysphagia in children, the Feeding/Swallowing Impact Survey (FS-IS; Lefton-Greif et al., 2014) was developed, which is an inventory (an 18-item tool) designed 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. However, this is specific to very young children (median age of the sample = 14 months, interquartile range = 7–35 months). Moreover, this was developed to measure the impact of feeding/swallowing problems on caregiver health-related quality of life.

Informal caregiving services often go unnoticed, causing unintended burdens (Adelman et al.,2014; Wolff et al., 2016). There is an increased dependence on caregivers to meet the requirements of the care recipients with dysphagia. The services and support caregivers provide extend beyond the mere support provision corresponding to dysphagia-related mealtime activities. Care recipients are the primary focus in most published literature on dysphagia, with limited attention on the family's needs. For the health and well-being of caregivers and their care recipients, identifying and managing this accompanying burden of care is necessary (Lyons & Lee, 2018; Pucciarelli et al., 2018; Torti et al., 2004; Wolff et al., 2016). Explicit recognition of caregiver burden consequences assists the SLPs in drawing a plan for reducing such burden, maximizing the health outcomes of individuals, their significant others, and family members by including the same in the comprehensive dysphagia management strategy (Shune & Namasivayam-MacDonald, 2020).

Need for the study

The burden of care experienced by caregivers has been explored extensively in several different populations (e.g., stroke, neurodegenerative diseases, psychiatric disorders) till the present, but research on dysphagia-specific caregiver burden has surfaced recently.

The swallowing difficulties of the care recipients may lead to an increased burden on their caregivers. Early identification of dysphagia-specific caregiver burden and thecommencement of early intervention can improve the health outcomes and quality of life of the caregivers and their care recipients.

A screening tool that is quick, user-friendly, straightforward, understandable, and translatable across multiple populations is necessary for the early identification of dysphagia-specific caregiver burden in a multilingual country like India. Considering the increasing population of individuals with dysphagia in India and the increasein nuclear families, there is a need for a similar tool in the Indian context. In India, only among individuals with stroke, the pooled prevalence of dysphagia is 47.71% (95% confidence interval [CI] [20.49%, 70.92%], $p < .001$) (Krishnamurthy et al., 2022). This indicates a much higher prevalence of dysphagia in India when other resultant conditions of dysphagia are considered. Acknowledging the differences in the 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 Western findings in the Indian population, thus, necessitating a need for replications.

Presently, no standardized tool exists to evaluate and measure the dysphagia-related caregiver burden in any Indian language, including Malayalam. The Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) by Shune and Namasivayam-MacDonald in 2020 was developed as a screening tool and validated in English. This was a quick, simple screening tool to identify caregiver burden. However, the same cannot be directly used in the Indian scenario as the specific terms/phrases/questions in the questionnaire may not be applicable and may be too complex for India's general population to understand. The culture and beliefs revolving around eating and drinking could vary across the globe. Further, there could be other additional contributors or aspects of caregiver burden that may be relevant to the Indian context. This necessitates the need for the instrument to be adapted, translated, and validated. Hence, adapting and translating the Malayalam version of

CARES would help researchers and clinicians in India to document the burden of caregiving experienced by the caregivers of individuals with dysphagia who speak Malayalam. This would allow better clinical decision-making and the development of comprehensive and effective dysphagia management plans.

Aim of the study

The present study aims to transadapt the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES; Shune & Namasivayam-MacDonald, 2020) screening tool in Malayalam and validate the tool on caregivers of individuals with dysphagia.

Objectives of the study

1. To adapt and translate the caregiver burden screening tool CARES to an Indiancontext, the Malayalam version.
2. To determine the content and construct validity of the constructed Malayalam version of theCARES screening tool on carers of individuals with dysphagia.
3. To determine the reliability of the constructed Malayalam version of the CARES screening tool on carers of individuals with dysphagia.
4. To determine the association between the caregiver related variables such as age, gender, socioeconomic status, relationship status, and duration of caregiving services and the dysphagia-specific caregiver burden.
5. To determine the association between care recipient related variables such as cause of dysphagia, dependency status, feeding status, and duration of use of tube feeding and the dysphagia-specific caregiver burden.

Chapter II

Review of Literature

Swallowing or deglutition is the process in which food or liquid, or oral secretions (such as saliva) are transported from the oral cavity to the stomach via the passage of the pharynx and esophagus. The swallowing process begins to develop as early as the embryological stage in-utero, around 15 weeks of gestation, as a simple event of regulating the flow and volume of amniotic fluid into the foetus and evolves into a coordinated sequential mechanism by the early life of an individual (Miller et al., 2003). This highly coordinated neuromuscular process involves voluntary and involuntary sequential actions of over 30 or more nerves and muscles along the pathway from the oral cavity to the stomach (Jones, 2003).

2.1 Physiology of Normal Swallowing

Generally, the swallowing process in an individual is mainly divided into three phases, namely, the oral phase, the pharyngeal phase and the esophageal phase with respect to the site of bolus in its journey to the stomach, where the oral phase consists of oral preparatory and oral propulsion stages (Dodds et al., 1990; Logemann, 1998). The sensory awareness of food or liquid (i.e., sight, smell, feel) activates the nerves and muscles involved in deglutition for the acceptance of food into the mouth, marking the onset of the swallowing process and its arrival in the stomach without going into the airway demarcates the end point of deglutition in a normal individual. The swallowing process for both the solid (or semisolid) food and liquid is different in the oral phase as the way in which food and liquid are manipulated in the oral cavity and transferred into the oropharynx differs, whereas the manipulations undergone at the pharyngeal and esophageal phases for both boluses are similar.

The oral phase being the voluntary phase, begins when the food or liquid is received into the mouth. For liquids, the lips and tongue make a seal anteriorly, while soft palate elevation and back of tongue retraction make a seal posteriorly to secure the bolus in the oral cavity without resulting in spillage (anterior or posterior) and then transferring the liquid bolus into the oropharynx as a result of the posterior and superior tongue movements. For solids, once the food enters the mouth following the lip closure, it is manipulated via mastication to form a bolus, following which it is transported to the oropharynx through cyclical movements of the tongue to initiate the pharyngeal swallow.

The pharyngeal phase of swallowing, being partially voluntary and involuntary, is the shortest, most complex and highly coordinated phase controlled by the swallow centres in the brainstem. It initiates once the bolus reaches the oropharynx with simultaneous velopharyngeal closure and proceeds with other sequential neuromotor coordinated events required for the safe transportation of the bolus till it reaches the upper esophageal sphincter (UES), which demarcates the beginning of esophageal phase. The bolus is carried through the esophagus by its peristaltic wave motion under involuntary control till it reaches the lower esophageal sphincter and stomach, which ends the process of deglutition (Matsuo & Palmer, 2008).

2.2 Dysphagia: Abnormal Swallowing

Dysphagia or impaired swallowing is the manifestation of numerous structural or physiological abnormalities of the structures or muscles or nerves involved in the process of eating and deglutition. Head and neck cancer (HNC), cerebrovascular accidents (CVA), traumatic brain injury (TBI), brain tumour, neurological disorders (such as Parkinson’s disease, Amyotrophic lateral sclerosis, multiple sclerosis, muscular dystrophy, Alzheimer’s disease, dementia, etc.), iatrogenic factors etc. are some of the major causes of dysphagia.

Based on the site and phase of swallowing that is affected, dysphagia can be classified into oropharyngeal dysphagia and esophageal dysphagia. Neurological damage (such as TBI, CVA, spinal cord injury), neurological disorders (such as Parkinson’s disease, Alzheimer’s disease, muscular dystrophy, ALS, Multiple sclerosis etc.), Head and neck cancer and its treatments (such as prolonged radiation), infections of CNS (such as poliomyelitis, encephalitis etc), Zenker’s diverticulum etc. are some of the etiologies of oropharyngeal dysphagia. Achalasia, neurological disorders, CVA, TBI, Gastroesophageal reflex disorders (GERD), esophageal strictures, esophageal neoplasms, esophageal spasms, esophageal stenosis, esophagitis, esophageal diverticulum, radiation therapy etc. are some of the causes of esophageal dysphagia.

2.3 Prevalence and Incidence of Dysphagia

The prevalence of dysphagia was found to be 45.3% by Hutcheson (2019) in HNC survivors aged 65 years and above based on their data obtained from Surveillance, Epidemiology, and End Results (SEER)-Medicare database. The prevalence of dysphagia was found to vary between 37 and 78% in individuals with TBI, as reported in the studies of Silva et al. (2012), Bremare et al. (2016) and Ferrucci et al. (2019). The meta-analytic study carried out by Gong et al. (2022) on individuals with Parkinson’s disease (PD) estimated the pooled prevalence rate of dysphagia to be 36.9% to 57.3%, with Asia being in the third position with a prevalence rate of 38.6%.

In the cross-sectional study carried out by Husmeela et al. (2021) on 104 individuals with HNC, the prevalence of dysphagia was identified to be 43.3% among patients with HNC. The majority of the patients with dysphagia were Indians (60.0%), followed by Malays and Chinese. Krishnamurthy et al. (2022), in their research among individuals with stroke in India, identified the pooled prevalence of dysphagia to be 47.71% (95% confidence interval [CI; 20.49%, 70.92%], $p < .001$).

2.4 Symptoms and Consequences of Dysphagia

The person with dysphagia may experience difficulty chewing, difficulty holding bolus in the mouth resulting in anterior or posterior spillage of food or water, nasal regurgitation, choking, coughing, gagging, pain during the swallow, penetration, aspiration, globus sensation or foreign body sensation in the throat or chest area, change in voice after swallowing, pneumonia, chest pain, malnutrition, dehydration, weight loss etc. as common symptoms (Mayo Foundation for Medical Education and Research, 2022). Persistent or continuing aspiration pneumonia, dehydration and malnutrition reduce the individual’s immunity and increase their mortality.

Apart from the above-given direct complications of dysphagia, it exhibits several other complications in the lives of the patients and people in their vicinity. It causes financial burdens (Patel et al., 2017; Jukic et al., 2019), emotional and psychological burdens (Ekberg et al., 2002), social burdens (social withdrawal and isolation) (Ekberg et al., 2002), reduced rehabilitation capabilities, increased visits to health care centres and use of health care services (Attrill et al., 2018), and decreased self-esteem and quality of life of both individuals with dysphagia and their caregivers.

2.5 Assessment and Management of Dysphagia

Studies have highlighted the necessity of early detailed assessment, rehabilitation, and regular follow-ups of individuals with dysphagia as it has proven detrimental to the patient, spreading its lasting consequences to both the patient and their caregivers if early and appropriate action is not taken (Christmas & Rogus-Pulia, 2019). Christmas and Rogus-Pulia (2019) have reported that dysphagia increases the risk of pneumonia, dehydration, weight loss, and caregiver burden and reduces both the patient’s and their caregiver’s quality of life with increased mortality risk over time. These dysphagia consequences tend to aggravate with time if not diagnosed early. Early detection and treatment of dysphagia by SLPs improves quality of life and lowers the risk of subsequent medical issues and mortality.

There are several tools available to assess the swallowing function, reach a diagnosis of dysphagia, and see its impact on the individual. Bedside screening tests/clinical swallow examination and instrumental evaluation are the main ways of assessing swallow functions. The clinical bedside examination is the first and foremost assessment carried out prior to instrumental evaluation. The collection of the patient’s current medical status and medical history, cognitive and communication abilities, physical swallowing musculature examination, and oral feeding trials with different consistencies and volumes are performed during the clinical examination. Four finger test (Logemann, 1998), dry swallow test, repetitive saliva swallow test (RSST; Oguchi et al., 2000), water swallowing test (DePippo et al., 1992), the Gugging Swallowing Screen (GUSS; Trapl et al., 2007), the Eating Assessment Tool (EAT-10; Belafsky et al., 2008), Nair Hospital bedside swallowing assessment (NHBSA), etc., are some commonly employed bedside screening tests. The Manipal manual for swallowing assessment, given by Kumar and Bhat in 2012, is a comprehensive manual that can assess the structure, function, and phases of swallowing in adults and geriatrics. Fiberoptic Endoscopic Evaluation of Swallowing (FEES; Langmore et al., 1988), Videofluoroscopic Swallowing Study (VFSS; Logemann, 1986), Electromyography (EMG), barium swallow techniques, video radiographic techniques, imaging techniques (CT scan, MRI etc.), high-resolution manometry etc. are the commonly employed instrumental evaluations to diagnose dysphagia.

The management options for dysphagia mainly revolve around compensatory or facilitatory approaches. These techniques improve an individual’s swallowing functions by reducing or eliminating the occurrence of dysphagia symptoms. Compensatory techniques do not improve the swallowing physiology directly but modify an individual’s swallowing by reducing or eliminating the symptoms of dysphagia through oral hygiene maintenance, dietary and bolus modifications, postural compensations and swallowing facilitative manoeuvres and devices. Facilitatory techniques, on the other hand, directly improve the swallowing mechanism through exercises that improve the strength and coordination of muscles and the sequencing of events involved in swallowing.

2.6 Tube feeding and Oral Feeding Determinants

In patients who had a CVA, TBI, or neurodegenerative conditions, there are high possibilities for the requirement of tube feeding to ensure intake of adequate nutrition by the patient and prevention of airway complications and may result in either long-term or short-term nonoral intake (Darbar, 2001; Holmes, 2011; Kobayashi et al., 2002; Thomson et al., 2002; Zhang et al., 2012). HNC patients also rely on nonoral intake depending on their lesion site, the extent of the lesion, the extent of surgical removal of structures and post-radiation complications. The major reasons for the recommendation of feeding tubes in individuals with dysphagia include compromised airway protection during swallowing and the inability to meet nutritional requirements via oral intake. At times, the patients may also require supplemental enteral nutrition in addition to oral feeding to meet the nutritional requirements.

There are several types of enteral nutrition depending on the site and procedure of insertion of the feeding tube, a few of which include nasogastric tubes (NGTs), gastrostomy tubes (GTs), jejunostomy tubes (JTs), percutaneous endoscopic gastrotomy (PEG) tubes etc. A specific nonoral feeding technique is selected depending on the patient's health, the nature of the underlying ailment, multiple clinical factors and the timing and method of reintroducing oral feeding. While NG tubes are recommended in acute stages of the disease (placed in situ for no longer than 4 to 6 weeks), a PEG tube or GTs can be opted for in cases of long-term enteral nutritional requirements (more than 4 weeks or 6 weeks period of time) since it has comparatively fewer long-term use complications than NGTs (Abuksis et al., 2004; Bankhead et al., 2009; Stroud et al., 2003). However, tube feeding is considered a temporary management option for swallowing issues. Once the underlying disease or other conditions contributing to dysphagia are resolved or once consistently safe and efficient swallowing is determined through instrumental and clinical evaluation, transition to oral feeding can be pursued in the patient. Swallowing therapy has also been proven to improve an individual’s swallowing abilities, eliminating the need for enteral nutrition and facilitating oral feeding in patients. Once the patient is able to ingest adequate food and liquid to meet appropriate nutritional needs, along with achieving the physiological ability to transfer the bolus safely into the esophagus and improved cognitive status, the return to oral intake is recommended (Crary & Groher, 2006). The functional Oral Intake Scale (FOIS) is a tool that helps to determine the functional level of oral intake by a patient with dysphagia. The International Dysphagia Diet Standardisation Initiative Functional Diet Scale (IDDSI-FDS) is another tool which provides information on the diet status of the patient with scores 0 to 8, where a score of 0 or near 0 is indicative of high diet restrictiveness and a score of 8 is indicative of an unrestricted diet.

2.7 Caregiver Burden in Dysphagia

Dysphagia impacts not only the individual suffering from it but spreads its devastating effects to those in the vicinity of the patients as well. Several studies report physical burden, psychological burden, social burden, financial burden, etc., related to dysphagia among caregivers of individuals with swallowing issues. This has also been shown to impact the caregivers’ and care recipients’ daily activities and quality of life. The caregivers of dysphagics frequently report of a lack of sleep or disrupted sleep patterns, weight loss, and fatigue that came along with their overloaded roles and responsibilities, resulting ultimately in a reduction in their overall physical health. The care recipient’s modified diet plan and diet restrictiveness, high chances of coughing and choking while eating and drinking, inability to participate in social gatherings and eating outside, disrupted meal time, the expenses associated with nutritious foods, supplements, tube feeding etc., give rise to several negative emotions like frustration, stress, fear, tension, depression, loneliness, etc. among their caregivers contributing to the psychosocial and financial burden experienced by the caregiver.

2.7.1 Studies that Investigated Dysphagia-Related Caregiver Burden

Swallowing and eating disorders significantly impact the lives of parents caring for their children (older or adult children) with dysphagia, as Hillege (2006) reported from a semi-structured interview with 22 parents of patients with dysphagia. His study categorized the consequences faced by the parents of an individual with dysphagia into five themes after an in-depth analysis of their reported experiences. The five themes mainly comprised emotional impact, social impact, financial impact,

impact on the family, and inconsideration of dear ones. One’s children’s dysphagia resulted in family rifts, emotional stresses and difficulty coping, reduced social interaction, social exclusion and isolation, financial difficulties, unsupportiveness and inconsideration from other family members or friends.

Johansson and Johansson (2009) aimed to describe the experiences of relatives due to a family member’s eating and swallowing difficulties and the impact of it on their daily life and lifestyle. The nine caregivers, recruited through snowball sampling and interviewed, revealed increased responsibilities and demands due to the care recipients’ swallowing difficulties in terms of appropriate meal preparations, tube feeding-related concerns and the increased duration spent for the same, causing hindrance to their working hours. They reported the loss of social interaction during meal times and exhibited feelings of concern, stress, grief, discomfort, frustration, isolation, loneliness, insecurity, worry and anxiety pertaining to dysphagia-specific concerns.

The systematic review performed by Namasivayam-MacDonald and Shune (2018) intended to understand the caregiver burden among caregivers of the elderly aged 60 years and above who have dysphagia. Caregiver burden in elderly dysphagics was analyzed from the findings of four criteria-met articles, restricted to English and from 1900 to 2018, obtained from several electronic search databases like PubMed, Embase, Cochrane, Medline, Web of Science, and CINAHL. Their review found a hike in the caregiver burden if the elderly care recipient had dysphagia and was associated with worsened feeding behaviors of the care recipient over time, based on interview responses, the Zarit Burden Scale and the Sense of Competence Questionnaire (SCQ; Vernooij-Dassen, 1993) response scores obtained from the selected studies. They also reported that dysphagia was associated with a “heavy burden” if the care recipient was tube-dependent for feeding. The study could not conclude any specific reasons for the caregiver burden among caregivers of the elderly dysphagics because of divergent methods used to measure it.

Shune and Namasivayam-MacDonald (2019) investigated the type and extent of burden experienced by spousal caregivers of older adults reported with dysphagia associated with diverse etiologies through a cross-sectional study. The data of 422 older adult dysphagics (mean age: 77.3 years; 249 elderly males) and their spousal caregivers (mean age: 73.5 years; 250 elderly females) from NHATS and NSOC surveys were short-listed and subjected to in-person interviews for data collection. The spousal caregivers of 72 care recipients who self-reported dysphagia symptoms were finalised. They were found to experience a significantly increased emotional burden ($p = 0.038$), rated moderate to severe, as a consequence of dysphagia based on the logistic regression analysis results even when other influencing factors of caregiver burden were controlled. The caregivers reported feeling depressed, lonely, hopeless, and unappreciated, with the majority rating this emotional burden as moderate to severe. Highly educated female caregivers were found to most likely experience greater emotional burden, whereas the caregivers experienced comparatively less burden when the care recipient had better memory capabilities. They described the entangled association between the health and well-being of both the caregiver and care recipient dyads and emphasised the necessity of intervention plans to be unlikely limited to the care recipient alone.

In the cross-sectional study conducted by Namasivayam-MacDonald and Shune (2019), the influence and contribution of swallowing impairment to the caregiver burden in adult-child caregivers (n=182; age range: 19–72 years; females: 119) of ageing parents self-reported with dysphagia and aged 65 years & above were assessed through interviews. 895 caregivers’ data were shortlisted from the National Study of Caregiving (NSOC) data of caregivers collected through the National Health and Aging Trends Study (NHATS) survey, where 182 were carers of parents with dysphagia, and 713 were carers of parents without dysphagia. The type and severity of burden they experienced were assessed in terms of physical, emotional &/or financial burden. The results obtained after appropriate regression analysis revealed an increased physical and/or emotional burden, rated moderate to severe, experienced by the caregivers of adults reporting dysphagia symptoms. The adult child caregivers were found not to experience any significant dysphagia-specific financial burden, and this was attributed to insufficient data on more expensive nutrition-requiring rehabilitative measures. An increase in and managing additional responsibilities contributed to their physical burden, whereas fear, anxiety, frustration, guilt, loneliness, depression, and social withdrawal associated with their care recipient’s swallowing difficulties contributed to their increased emotional burden. These emotional burdens result from their care recipient’s social withdrawal, anxiety, and frustration during mealtime and from managing their restricted diet, choking issues, and nutritious diet. This study, however, lacks a causal relationship because of its use of secondary data along with the missing information regarding the formal diagnosis, type and severity of care recipient’s dysphagia.

The experiences of caregivers of adults with dysphagia in light of third-party disability during the in-home management (dietary modifications) of swallowing issues were described by Coutts and Solomon’s (2020) qualitative study in the context of an economically developing country like South Africa. Using phenomenological principles and themes of ICF domains, data was collected from seven care recipients with dysphagia (mean age: 47 years; females: 4) and six caregivers (male:3, female:3) through semi-structured interviews. Most patients had Motor neuron disorder (n=4), while others encountered TBI, oesophageal cancer and self-extubation trauma. Two participants depended on PEG feeding, while all others were on dietary modifications. The thematic data analysis technique revealed that the caregivers experienced financial burden and fear of managing nutritional requirements, tube feeding, and the consequences of dysphagia. Several other domains (namely activities, participation, environmental factors and personal factors) in the International Classification of Functioning, Disability, and Health were also affected, which negatively influenced the carer’s daily functioning. This study identified third-party disability to be experienced by all the participant caregivers and the use of diet modification as the most suitable and convenient dysphagia management approach to be adopted in scenarios with access and contextual limitations. They emphasised not only the importance of caregivers and family members being part of a long-term dysphagia management plan but also the need to consider the caregiver’s needs and well-being for better outcomes. However, the small sample size and the study being performed only in the urban setting proved to be significant limitations of this study, along with the unavailable data on the duration of dysphagia and caregiving services.

Ninfa et al. (2021) explored the care needs of adults with oropharyngeal dysphagia and their informal caregivers associated with dysphagia management over the past 20 years (2000 to 2021) through a scoping review following the PRISMA guidelines. The majority of the care recipients had dysphagia associated with HNC (8 out of 15 studies), while others had neurodegenerative conditions or a miscellaneous diagnosis. 266 care needs were totally identified by them from 15 selected Western studies, which were classified under 5 categories, namely, practical needs (associated with meal management and food availability), informational needs, social needs, psychological needs, and physical needs (associated with tasty diet consumption and learning techniques to improve feeding and swallowing abilities) using a “best fit” framework synthesis approach. They recognized social and practical needs as the primary necessity, followed by informational and psychological needs in both informal caregivers and their care recipients, with a minority of them reporting physical needs also. The limited number of studies reviewed and the lack of studies on heterogeneous etiologies of oropharyngeal dysphagia prevents the generalization of the results of their investigation.

The systematic review performed by Rangira et al. (2021) studied the consequences of dysphagia associated with any aetiology on caregivers of adult care recipients and its impacts on their caregiving services. 17 target-met Western studies finalised from different search databases revealed a negative impact and increased burden associated with caregiving for all caregivers of adults with dysphagia. These results were consistent irrespective of caregiver and care recipient-associated variables such as age, gender, the relationship between both and the aetiology of dysphagia. Meta-analysis results of this study revealed that about 71% of the carers of adult dysphagics face some degree of dysphagia-specific caregiving burden. Changes in mealtime activity, modified meal preparations, deviation from regular lifestyle, disruption in social-emotional well-being, responsibilities associated with tube feeding, and fear of aspiration were found to be associated with this increased caregiver burden. This study revealed dysphagia-specific negative impact contributing to the caregiver burden and causes of these burdens in general, providing more insight for better therapeutic intervention for the caregiver-care recipient dyad. However, the study did not mention aetiology-specific delineation of the dysphagia-related causes of the caregiver burden.

In the critical review published by Hassib and Ostia (2021), the dysphagia-related burden and stresses experienced by the primary caregivers of adults with swallowing impairment were summarised. A total of 6 articles pertaining to caregiver burden in dysphagics were reviewed. All the articles reviewed revealed the occurrence of caregiver burden among carers of individuals with swallowing impairment. The findings concluded dysphagia to be an independent predictor of the caregiver's experienced burden from their caregiving services to individuals with dysphagia. They identified increased levels of anxiety, disrupted social connections, increased responsibilities concerning meal time, diet modification, and feeding tubes, and increased emotional, physical, and financial burdens specific to caring for individuals with dysphagia. Their findings summarized dysphagia as not limited to a single individual but as the cause of psychological stress on the entire family unit, especially their primary caregivers. Hassib and Ostia suggest the need to recognise and manage these burdens to enhance both the caregiver's and care recipient's overall health and well-being. However, there are chances for the findings presented to be biased due to the selection of the majority of the articles published by the same author, which were carried out on the same population, that is, the caregivers of the elderly population with dysphagia. This drawback was attributed to the limited research data available on their study topic.

Coutts and Sayed (2023) attempted to describe the third-party disability of the primary caregivers (i.e., family members) of adults with dysphagia in an urban context in South Africa. Caregivers who participated were above the age of 18 years, provided care services for individuals with oral and pharyngeal dysphagia associated with neurological conditions (either CVA, epilepsy, motor neuron disease, or head injury), and carried out in-home management in terms of dietary modifications. The participants completed the Adult Carer-Quality of Life (AC-QoL; Elwick et al., 2010) questionnaire, and the most weighted aspects from it based on the participant’s responses were used for the semi-structured online interview. They related the caregiving issues reported by the five informal primary caregivers of persons with dysphagia during the interview to the domains of the International Classification of Function and Disability (ICF). The results revealed third-party disability (TDP) among the caregivers, the issues reported being categorized majorly under the ICF domains of activities and participation, followed by environmental and personal factors. There were even reports of emotional burden (stress, depression, frustration, concern, fear, etc.), financial burden, independent factors like COVID-19 consequences, which resulted in reduced support from others for care and assistance, and rare reports of aspects of body structure and function affected (such as weight loss & disturbed sleep patterns due to stress) as a consequence of dysphagia in the caregivers. The TPD was found predominantly to be with respect to increased time demands and responsibilities, and difficulty performing their activities of daily living, completing the household chores, planning of modified diet, preparation of adequately nutritious meals, along with limited social activities and engagements. Healthcare personnel must be mindful of the TPD’s impact when developing home management methods. This newly developed depiction of dysphagia-specific caregiver burdens makes health personnel mindful of the impact the TPD can have and work towards developing an appropriate in-home patient-centred treatment strategy.

2.7.2 Caregiving in Individuals with Head and Neck Cancer

Nund et al. (2014) conducted a qualitative descriptive study on twelve caregivers of individuals with HNC undertaking treatment and under non-gastrotomy feeding since 2007. The caregiver participants, who fell between the age range of 45 to 67 years, were interviewed in-depth regarding the consequences faced due to their caregiving services. Participant variables such as caregivers’ and their care recipients’ age, caregivers’ gender, treatment duration, relationship status, relationship duration, and caregiver’s occupational status were collected. They identified that the dysphagia-related caregiving burden experienced by the caregivers of individuals who underwent non-surgical management for HNC disrupted their lives dramatically. Four themes were finalised through thematic analysis based on the information obtained from the carers regarding their stresses. The finalised themes were: (1) Dysphagia hinders everyday activities and functioning; (2) caregivers make adaptations to their care recipient's swallowing impairments to establish a “new normal”; (3) the gap between caregivers' desired outcomes and dysphagia reality; and (4) experiences with dysphagia-related support facilities, aids and assistances. Caregivers were often found to be unprepared and burdened for their part in dysphagia rehabilitation. They reported these burdens to be associated with changes in the meal preparation and diet of the care recipient, socio-emotional disruption, changes in the family life, activity limitations such as reduction in eating out, and their increased responsibility to deal with the consequences of dysphagia. Since this study comprised a heterogeneous group of subjects who were at various stages of recovery following treatment, it could not be figured out when difficulties were more significant or when adjustments happened across different timelines following treatment.

The third-party disability in caregivers of individuals with dysphagia following HNC, who underwent non-surgical management from 2007 to 2012, was determined and documented by Nund et al. (2016) using the ICF framework. From the semi-structured, in-person, in-depth interview conducted by them on twelve caregivers of individuals with dysphagia post-HNC treatment, the information collected could be categorized (19 categories) and sub-categorized (26 sub-categories) on behalf of the four themes identified from their previous study. 34/45 of these categories and sub-categories could be associated with the 29 ICF codes across the three domains of the ICF model (Body Functions, Environmental factors, and Activities and Participation), with most of it (17 items) falling under the Activities and Participation domain of the ICF framework. Frustration, anxiety, concern, and pity were among the feelings linked to the ICF. Caregivers revealed emotions corresponding to the mealtime changes and modified food preparation, dysphagia consequences, namely, aspiration and choking, and their care recipient's notable drop in weight. Eleven categories failed to be coded under any of the ICF domains. These included items pertaining to Personal Factors (negotiating and embracing a new normal, attitude, staying optimistic, going out for meals with friends, etc.) and items not addressed by the ICF (recuperation-related assumptions, "adaptation needs time", and "it got harder after the treatment"). Premorbid psychological states of caregivers, along with the caregivers’ all possible postmorbid emotional burdens experienced, were not mentioned in the current article.

Penner et al. (2012), through a descriptive phenomenological in-person interview, studied and attempted to address the caregiving experiences of family caregivers of individuals with HNC relying on tube feeding. The caregivers (four females and two males) selected, aged between 49 and 64 years, were either spouses or siblings of the person with dysphagia and lived with the patient. Two comprehensive interviews were conducted for each of the six family caregivers recruited for the study, and the data collected were analysed using Spiegelberg's three-step technique. "Negotiating a new normal" was discovered as the core consequence of family caregivers' adaptation to dysphagia, which encompassed four themes such as: "negotiating changing roles", "negotiating an altered lifestyle", "negotiating ways of coping", and "negotiating the meaning of the feeding tube". They identified that caregivers faced several stresses. They were found to adopt a new normal lifestyle as a result of their caregiving services, which corresponded to the issues related to increased responsibilities and changed roles, altered lifestyles, tube feeding, and coping strategies. The current study discussed themes 1 and 2. The caregiver participants reported significant difficulties balancing the responsibilities and demands faced while managing multiple roles together. The reports suggest feelings of frustration, anxiety, fear, and unpreparedness in caregivers with regard to the significantly changed responsibilities and the inability to achieve them. The strict schedule that came with tube feeding in caregivers' lives left them with a lack of leisure time, altered sleep patterns, and impaired mealtime activities and social life. The study concluded that participants were found to experience an increased physical and psychological burden related to dysphagia-specific caregiving services.

The longitudinal qualitative study conducted by Hiatt et al. (2021) investigated the nutritional care experiences of caregivers and their care recipients from the time of diagnosis to one year post-HNC treatment. Twenty HNC patients and fifteen caregivers with a mean age of 59 and 55 years were interviewed four times at different interval periods (prior to treatment, at two weeks post-treatment, at three months and at twelve months after treatment completion). Three out of the total thirty-five participants were caregiver-care recipient duos, and 11 patient participants and care recipients of 12 caregivers depended on tube feeding. The results revealed a negative emotion of distress in both the carer and the patient participants. The emotional distress in caregivers was found to be associated with weight loss and loss of muscle mass and strength of the care recipient, their struggle to maintain their own physical well-being, and reduced health professionals’ support and guidance post-treatment completion. Their findings also reported caregivers' regard of the gastrostomy tube as a crucial aspect of treatment and a means to assist their partner's nutrient intake when food and liquid consumption became unmanageably problematic. Through thematic analysis, the authors categorized the participants’ reported experiences into two major themes: the struggle to retain control and manoeuvring the challenges ahead. This study suggests the necessity for developing nutrition care techniques that take the caregiver-partner pair into consideration.

A qualitative inductive study was carried out by Hiatt et al. (2022) to understand the nutrition care experiences of caregivers (*n*=14) of individuals with dysphagia post-HNC treatment. All the participants were aged above 18 years, and the majority were female caregivers (*n*=13). The caregivers of individuals who underwent surgery with postoperative radiation therapy and carers of those who underwent radiation therapy with concurrent chemotherapy were interviewed at 2 weeks, 3 months, and 12 months after treatment completion to assess their experiences with nutrition care. Thematic analysis was done to identify the differences in caregiver experiences of dietary management between surgical treatment and radiation therapy. Two major themes were observed across both therapeutic methods: (1) access to information and assistance from healthcare providers and (2) adaptation to the mental and physical consequences of treatment. Both the caregiver groups experienced some degree of psychological impact (such as frustration, guilt, fear, distress, fatigue, and burnout) along with reduced social interactions and withdrawals post-surgery or radiation therapy. They highlighted the need for the provision of organised and systematic nutrition care support for caregivers in the clinical and outside-clinical context to lessen their supportive care demands throughout the caregiving period.

2.7.3 Caregiving in Individuals with Stroke

Survey research was executed by Byeon (2019) on eighty-three caregivers of stroke survivors with dysphagia aged above 18 years, with a majority above 50 years of age (*n*=64) and 78.8% female participants (*n*=66). The participants recruited were spouses, children or paid caregivers of persons with dysphagia with either oral or nonoral food and liquid intake (oral intake: 38 care recipients). The study aimed to identify the extent of caregiver stress. In this study, he used Kim & Roh's (2005) tool that assesses the caregiving consequences in family caregivers of stroke patients with necessary modifications to measure the caregivers' stresses. The results revealed a severe burden, especially in terms of financial burden while caring for stroke patients. The burden experienced was also associated with the patient's extreme dependency on the caregiver and the caregivers' apprehension about the care recipient's life ahead. The most worrying factor was found to be the care recipient's prognosis among the caregivers. Byeon also tried to identify the knowledge about dysphagia in caregivers and the preventive measures and practices they carried out concerning aspiration. He used the questionnaire by Song and Park (2012) to assess the caregivers' insight into dysphagia rehabilitation and Kim and Kim's (2012) tool about preventive measures for aspiration pneumonia in the elderly to assess the attitude towards aspiration pneumonia prevention in dysphagics. He identified the informal caregivers of stroke patients, especially spouses and children, as having insufficient knowledge compared to formal caregivers concerning dysphagia management and prevention of aspiration pneumonia, especially regarding the negative consequences of long-term NG tube usage. According to the findings of this research, the loved ones caring for a stroke survivor also encounter a lack of social activities because of their daily life constraints and experience extensive burdens because of the medical expenditures incurred as a result of the prolonged illness duration.

The investigation conducted by Davis et al. (2021) studied the post-stroke dysphagia-specific caregiver burden and care recipient- and caregiver-perceived dysphagia impact on mealtimes. They surveyed 28 stroke patients with swallowing impairment and their spousal caregivers. Scores for dysphagia-related caregiver burden, social and mealtime logistics based on both caregiver and care recipient perceptions, aligned perspectives of the perceived consequences, IDDSI Functional Diet Scale, SWAL-QoL Scale, and Stroke Impact Scale were calculated. Their study showed an increase in caregiver burden associated with a greater patient- and caregiver (spouse)-perceived dysphagia impact on mealtime logistics, increased diet restrictiveness, and dysphagia-specific reduced quality of life. The burden was found to be not associated with the dyadic congruence of the impact perceived by both the spousal caregiver and the care recipient, as well as the severity and impact of the stroke. Their study concluded that dysphagia-specific caregiver burden is multifactorial and associated with both caregiver and care-recipient factors.

Horyacheva et al. (2022) published an article regarding their findings on the stroke survivor-spouse relationship post-stroke, and the association between the relationship congruence and swallowing-related quality of life (SWAL-QoL) and caregiver burden experienced due to dysphagia. Twenty-nine couples completed a 15-item relationship questionnaire along with SWAL-QoL and a measure assessing the dysphagia-related caregiver burden associated with mealtime togetherness and social aspects. Spearman’s correlation analysis assessed the correlation between relationship congruence and dysphagia-specific caregiver burden and SWAL-QoL scores. Their findings revealed communication, affection, and honesty to be the most commented positive spousal relationship strengths. The statistical analyses performed suggested no significant correlation between relationship congruence and SWAL-QoL or dysphagia-specific caregiver burden post-stroke in the spouses.

2.7.4 Caregiving in Individuals with Neurological disorders

In a survey study, Arslan, Demir, and Karaduman (2017) looked into the relationship between caregiver anxiety and patient-related variables in neurological patients with dysphagia. A total of 103 patients who were diagnosed with dysphagia for more than one month and had an EAT-10 score of three or higher and their caregivers, both aged 18 years and above, were recruited as the study group, whereas 30 pairs of caregivers and neurological patients without dysphagia served as the control group in this study. The selected participants were diagnosed with either cerebrovascular accident, multiple sclerosis, myasthenia gravis, or Amyotrophic lateral sclerosis with a wide range of severity of dysphagia. The authors gathered the participant's demographic data, including the patient's age, gender, height, weight, diagnosis, feeding methods, dependency level when it comes to eating and drinking, the duration of diagnosis of dysphagia, and history of earlier dysphagia treatments. Turkish EAT-10 (T-EAT-10; Demir et al., 2016) and VFSS were performed to confirm the diagnosis of oropharyngeal dysphagia in the study group. Using the State-Trait Anxiety Inventory (STAI; Spielberger et al., 1983), they gathered data on the anxiety level of the caregivers. According to their research, caregivers of individuals with dysphagia had higher STAI scores than caregivers of those without dysphagia and, as a result, reported more anxiety. However, the history of prior treatment for dysphagia was the only factor significantly correlated with caregiver anxiety and patient-related characteristics. There was no association between STAI and T-EAT-10, penetration-aspiration scale (PAS; Rosenbek et al., 1996), feeding types, dependent conditions for eating and drinking, or duration of dysphagia ($p > 0.05$). According to them, providing treatment for neurological patients with swallowing difficulties may result in a greater financial burden on the carer, increasing their anxiety levels. The rehabilitative professionals must provide additional support to meet these caregivers' increased requirements. This study offers solid proof of the physical and emotional toll that carers of those with dysphagia bear.

Lisiecka et al. (2020) investigated the experiences of family caregivers and their caregiving burden in Amyotrophic Lateral Sclerosis (ALS) cases with dysphagia through a qualitative phenomenological study. In-person mega-interviews and mealtime observations during its preparation were carried out with ten adult caregivers of individuals with ALS and dysphagia residing in the southwestern part of Ireland. The lifestyle of the primary caregivers of persons with ALS was found to be disrupted as a consequence of dysphagia. Dysphagia in ALS individuals were found to change the mealtime experiences and environment and enhance the physical, psychological and emotional burden (frustration, distress, fatigue, fear, and guilt) among caregivers. The data revealed a general theme of "transformation of life" in caregivers after ALS diagnoses. Along with this, two superordinate and two subordinate themes also emerged from the findings of their study. The first main theme and its sub-themes talk about the act of caregiving for an individual with ALS and its consequences with respect to emotions, feelings and coping strategies. The second theme and subthemes were specific to mealtime, 'mealtime changes and its experiences', which revolved around choking while eating and the precautions adopted to ensure safe eating. Frustration at the failure to maintain the patient's weight and the fear of choking in their partners while eating were found to be significant emotional distresses in the caregivers. Constant monitoring was found to be offered by the caregivers to ensure a 'safe swallow' during mealtimes in individuals with ALS.

Perry et al. (2022) examined the influence of Parkinson's patient's swallowing difficulties on the quality of life of their primary caregivers, who mainly included their spouses. The study surveyed fifty caregivers of individuals with Parkinson's disease. Data collected were used to obtain the carer quality of life scores, presence of penetration-aspiration and pharyngeal residue as well as Parkinson's disease course. The statistical analysis revealed a significantly reduced quality of life and impaired adaptation abilities due to caring for the care recipient's mealtime and nutritional needs. All the care recipients were found to exhibit penetration and/or aspiration along with pharyngeal residue in some cases, but no significant association of it with the caregiver's quality of life was identified. They found that poorer caregiver quality of life was associated with the care recipients' combined impact of ageing and disease course. However, the study emphasised the limitation of existing methods in assessing the carers' quality of life, specifically due to dysphagia.

The pilot study conducted by Zimmerman et al. (2022) investigated the swallow-specific caregiver and care recipient quality of life in the Parkinson's disorder population. Thirty-six caregiver-care recipient dyads (mean age of caregiver: 65.9 years; mean age of care recipient: 70.8 years) participated in the study and filled out the online swallowing-related quality of life (SWAL-QoL) form. The mean SWAL-QoL scores of primary caregivers and their partners were compared, and the influential factors of SWAL-QoL scores were identified using appropriate statistical analysis. Factors like age, gender, racial or ethnic background, occupational status, history of dysphagia evaluation and intervention, patient's cognitive status and caregiver's concern, caregiver burden, and duration of illness were evaluated for correlation with the SWAL-QoL scores. The SWAL-QoL scores calculated were lower in caregivers and were related to increased caregiver's emotional burden associated with dysphagia management even though there were no significant differences between the obtained SWAL-QoL scores for patient and caregiver dyads. The paired caregiver and care recipient SWAL-QoL scores showed moderately consistent agreement. Caregiver burden was the sole significant factor that resulted in the caregivers' obtained SWAL-QoL scores. Reduced SWAL-QoL scores were found to be associated with caregiver burden in caregivers. No significant factors that were evaluated were found to influence the swallow-related quality of life in Parkinson's individuals.

In the observational cross-sectional study performed by Kalkers et al. (2022) among the caregivers (formal and informal) of individuals with Huntington's disease (HD) and the care recipients, the investigators tried to explore the difficulties faced by the caregivers (informal/formal) in a long-term care service. They also tried to explore the prevalence of dysphagia in Huntington's disease patients as well as the prevalence of fear of choking (FoC) and preventive measures employed in them. Huntington's Disease Dysphagia Scale (HDDS) (Heemskerk et al., 2014) and a question about being afraid of choking, along with the 'fear' subscale in the Dutch version of the SWAL-QoL (SWAL-QoL-NL; Bogaardt et al., 2009) questionnaire, were used to assess the prevalence of dysphagia and FoC in Huntington's disease. 158 patients and their caregivers were recruited for the study, and the patients were divided into independent groups and dependent groups on the basis of the Care Dependency Scale scores. The prevalence of dysphagia and FoC was found to be 90.5% and 51.9%, respectively, among HD patients. The FoC prevalence among formal and informal caregivers was 33.8% and 68.0%, respectively. A significant negative emotion was found to be associated with fear of choking among both the caregivers (especially among informal caregivers) and the care recipients based on the findings from the semi-structured interview and scores on the SWAL-QoL (pertaining to the ‘fear’ subscale). The findings reported speech-language therapy as the common method of dysphagia management according to the patients in both groups, while supervision during eating was the strategy used by formal caregivers in the independent group and diet modification by informal and formal caregivers. Informal caregivers also complained of early discontinuation of speech-language therapy and wished for extended availability of services.

2.7.5 Caregiving in Individuals with Intellectual Disability

The exploratory research conducted by Chadwick et al. (2006) on caregivers of adults with intellectual disabilities and dysphagia highlighted their perceived difficulties during implementing dysphagia rehabilitative strategies. Data from 46 caregivers (mean age: 48.19 years; 67.4% females) who catered to intellectually disabled adults’ dysphagia-specific needs was obtained through semi-structured interviews. The caregivers reported concerns related to appropriate food preparations and achieving safe consistency, appropriate positioning and posture during feeding, difficulties using the utensils recommended by the SLP, and difficulties monitoring the care recipient throughout their meal. Aspiration and asphyxiation were reported to be the main reasons for the caregivers to experience difficulties in achieving appropriate and safe feeding consistencies, and objections to modifications in meals by the patients were the reason for not complying with problematic strategies. Caregivers also expressed concerns with respect to time pressure, resource constraints, and changes of staff in between. Insufficient reviewing of the clinician-recommended dysphagia guidelines by the caregivers also posed a barrier to delivering safe and accurate care for swallowing problems. This study emphasizes the need for extra training and supervision for caregivers to recognize their roles better and understand their responsibilities in ensuring safe eating and swallowing for persons with dysphagia and intellectual disability.

2.7.6 Caregiving Burden in Children with Dysphagia

Follent et al. (2017) in their study explored the primary caregiver's perspective on the feeding difficulties faced while caring for their child with dysphagia post-ingestion injury associated with the consumption of button battery or chemical ingestion. The care recipient's presence of dysphagia was confirmed by the caregivers' responses to the modified Children's Picky Eating Questionnaire (CPEQ; Carruth & Skinner, 2002). All five primary caregivers interviewed were females. The caregiving services provided to the child with dysphagia, issues faced during the same, the impact of dysphagia on mealtime and the perception of their support needs and services were assessed through individual semi-structured interviews. Five primary themes were identified from the collected data which pertained to the specific challenges and experiences faced by the caregivers. These key themes emerged in relation to the child's initial trauma/injury event, subsequent swallowing difficulties of the child, and its impact on the caregiver and other family members, appropriate approach to dysphagia management at home, and other services and supports availed and challenges faced in the process. Their data revealed a significant negative impact on the caregivers in terms of increased responsibilities, psychological stresses, financial burden due to reduced work capacity and disrupted family mealtimes. The caregivers reported an impact on the wider family unit (such as affected relationship with other children due to constant hospital visits), constraints in availing appropriate services as well as a lack of adequate education and support for handling NPO feeding post-discharge from the hospital, which resulted in overwhelming feelings. This study suggests areas to be focused on to strengthen primary caregiver and family supports.

Pérez et al. (2022), in their descriptive observational study, aimed to describe the clinicopathological features of children with dysphagia from admission in a pediatric oropharyngeal dysphagia clinic, the burden and health-related quality of life (HRQoL) of their caregivers, and its impact on the family. A total of 103 patients were evaluated by the investigator. The majority of the pediatric patients evaluated had an underlying neurological condition (such as cerebral palsy, neurodegenerative disorders, etc.) and showed signs of dysphagia (oral, pharyngeal, and oropharyngeal), with most of them having oropharyngeal dysphagia as confirmed with VFSS. The results of this study revealed a direct correlation between the severity of oropharyngeal dysphagia and the presence of aspiration and degree of motor impairment in the children evaluated. A negative impact of oropharyngeal dysphagia on the day-to-day activities of their caregiver was identified based on the Swallowing Quality of Life Questionnaire. Their study discovered improved children's nutritional status and the caregiver's HRQoL with specialized care services offered by the pediatric dysphagia clinic.

The study conducted by Okada et al. (2022) aimed to determine the extent of community resource utilization and financial burden experienced by the caregivers of children with swallowing impairment between 0-5 years of age. The representative data was collected through a secondary analysis of the National Survey of Children’s Health data collected between 2017 and 2018. A total of 388,874 children with a mean age of 2.53 years and with feeding difficulties were identified, and their caregivers were surveyed to identify the financial burden faced due to swallowing problems. The results revealed increased financial burden and community resource utilization in children with feeding difficulties than those without. The caregivers of children with dysphagia suffered financial burdens with an expense of ≥$1000 with no job and scarce food availability. Most children with dysphagia experienced special education and/or developmental services, revealing higher community resource utilization than those without.

The increase in the burden across several aspects of the lives of caregivers and the negative impact spread over their lives as a consequence of their caregiving services for individuals with dysphagia affects their physical, mental and social health along with their economic well-being. These consequences, in turn, hinder their caregiving services and prohibit them from giving appropriate and necessary care to their dear ones with swallowing impairment. This takes a vicious cycle where the well-being of the caregiver deteriorates due to a lack of necessary and sufficient guidance and support, resulting in poor care and well-being of the care recipient. There is little or no emphasis given to this population up until recently. It is of dire importance to understand their stresses and devise a management plan accordingly, where caregivers and care recipients are met with necessary and sufficient help from the health care professionals and services. Currently, there are insufficient methods to assess the dysphagia-specific caregiving burden experienced by the carers of individuals with dysphagia, covering different cultural and linguistic populations worldwide.

2.7.7 Existing Tools to Assess Dysphagia-Specific Caregiver Burden and Quality of Life

Colodny (2008) developed and validated the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ) to assess the caregiver's compliance with SLP recommendations in regard to their care recipients with dysphagia. The items in the questionnaire covered three factors: quality of life issues, disagreement with the SLP, and avoidance of managing the feeding & diet modifications. Their study showed that caregivers with higher incomes and less frequent visits to the SLPs were likely to be not a close relative of the patient and prioritised the life quality issues more than the SLP recommendations. This questionnaire could give a vague idea about the caregiver burden as it has few statements indirectly suggestive of dysphagia-related caregiver burden.

The validated Feeding/Swallowing Impact Survey (FS-IS) instrument, developed by Lefton-Grief et al. (2014), assesses the impact on Health-Related Quality of Life (HRQoL) of caregivers caring for dysphagia-specific needs of younger children (mean age: 32 ± 44 months) with aspiration due to various aetiology. The 18-item questionnaire is divided into three subscales, namely, daily activities, worry, and feeding difficulties, to assess the dysphagia-specific consequences on the time demands of caregivers' day-to-day life activities, the emotional challenges faced during caregiving, and the difficulties experienced while feeding their loved ones. The responses rated on a 5-point Likert scale give the severity of the problem faced with a score of 1 indicating "never" and 5 indicating "almost always". The tool they developed could identify and track the dysphagia-specific needs of caregivers of children with swallowing problems.

Shune et al. (2020), in their article, highlight the development and preliminary validation of a questionnaire to screen for the dysphagia-related caregiver burden, the "Creation and Initial Validation of the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES)" screening tool. The 26-item tool, developed by a group of dysphagia research experts, is divided into two subscales, Part A and Part

B, with ten and sixteen items listed in both subscales, respectively. Part A of the screening tool contains items that screen for the behavioral and functional changes that occurred in caregivers' life as a consequence of dysphagia-related caregiving services, while Part B contains items that measure dysphagia-specific perceived stresses of the caregiver as a result of the same. The responses were noted down as 'yes/no' by the client, where a "yes" response was allotted a score of 1 and a "no" response a score of 0. Higher scores in both subscales were considered to be a higher dysphagia-specific burden experienced by the caregiver. The tool includes an additional question at the bottom of each subscale to elicit information regarding the most burdensome issues depicted in the statements in both subscales. The 26 family caregivers of individuals with dysphagia who completed the online survey mapped most of the items to fit the dysphagia-related consequences they experienced. Appropriate statistical analyses performed revealed internal consistency across the subscales and a significant correlation between CARES, the Eating Assessment Tool (EAT-10), the Zarit Burden Interview (ZBI), and the International Dysphagia Diet Standardisation Initiative Functional Diet Scale (IDDSI-FDS). This correlation was suggestive of increased dysphagia-specific caregiver burden with a perceived increase in swallowing difficulties, general caregiver burden, and diet restrictiveness.

Jain and Jagtap (2021) aimed to construct a tool in Marathi to assess the feelings, attitudes and quality of life of caregivers providing care services to individuals with dysphagia. The questionnaire was developed in Marathi, taking ICF codes and CMDQ as references. They administered the developed three-section questionnaire to thirty caregivers of adults with mechanical or neurological oropharyngeal dysphagia, among whom 15 were tube-fed. The three sections covered 42 statements or questions corresponding to the "activities of daily living and social

(ADLS)”, “feelings and attitudes (FA)”, and “feeding”. The 14 statements in the ADLS section assess the dysphagia effects on the caregivers with respect to mealtimes, daily activities, social participation, leisure times, job, and finances. The 12 statements in the FA section explore the caregiver’s attitude and emotions towards dysphagia and the concerns brought by it. The last section included 16 feeding-related statements, with six common statements for caregivers feeding their care recipients and five specific statements for oral and tube feeders each. Their findings revealed that the caregivers experience moderate to severe negative impact on their everyday activities, socialisation, feelings and attitudes and face significant difficulties during feeding. The questionnaire statistically showed significant reliability and internal consistency and is a good tool for measuring dysphagia-related caregivers’ QOL.

2.7.8 Strategies to Reduce Caregiver Burden

The tutorial published by Shune and Namasivayam-MacDonald in 2020 compiled the literature available on dysphagia-specific caregiver burden and associated third-party disability (TPD) among informal caregivers of individuals with dysphagia. They attempted to illustrate how rehabilitation specialists could employ these pieces of information to advise more specific treatment, optimise well-being, and improve caregiver quality 0of life. According to the authors, previous investigations that focused primarily on caregiver burden due to dysphagia yielded similar findings. They discovered that TPD, or restrictions in activity and participation as a consequence of the disability of a family member or friend, was frequent among carers of persons with swallowing difficulty. Family members experienced disruptions in their everyday activities and mealtime schedules, higher degrees of distressing feelings (distress, anxiety, frustration, despair, and solitude), reduced social ties, and reduced quality of life or contentment in life. They discovered that dysphagia was a distinct indicator of caregiver stress across investigations exclusive to this particular cohort. A lack of knowledge about swallowing issues, possible care-providing strategies, and available facilities, as well as the uncertainty and unpreparedness about the turn of events specifically due to dysphagia, all led to third-party disability and elevated caregiver stress. Several support strategies were also highlighted in their tutorial to reduce the caregiver burden and improve the self-efficacy of the informal caregivers, such as enquiring and listening to the caregivers' stresses, providing necessary education and facilities, arranging support groups, and meeting the needs of such a population. Hence, this literature review suggests ideas about genuine, practical guidelines for how therapists and professionals might influence the direction of their practice; however, these findings were obtained from a small pool of study data due to a shortage of existing literature in the particular area.

Howells et al. (2021) explored and described the caregiver's perspectives and experiences on supporting their family member/friend with dysphagia across diverse etiologies (e.g., CVA, Parkinson's disease, etc.) through individual semi-structured interviews. Participants recruited through convenience sampling were the primary caregivers of adults diagnosed with dysphagia, proficient in English, and with adequate cognitive competence. The investigation included 15 participants (females:13) ranging from 30 to 91 years of age and caring for 14 patients with dysphagia. The carers were either a spouse, a child, or a friend who lived with the patient. Common themes between the participants interviewed were discovered using the semantic technique. They discovered that the common theme in all caregivers, "you do whatever it takes", influences the three common sub-themes identified in the interviews: being a care provider, support systems, and the realities of living with swallowing issues. The data collected revealed that the participant's role as a caregiver impacted their mealtime engagements, psychological well-being, eating outside, and day-to-day life. The complexity of caregiving services, especially if associated communication difficulties are present in the individual with dysphagia, was found to negatively impact the caregiver in terms of their ability to provide optimal care and to understand dysphagia-specific consequences in one’s life and their own emotional stresses. Their study identified ease of burden of caregivers associated with dysphagia upon support from family, friends, and health professionals. The investigators concluded with a strong belief that these carers would "do whatever it takes" to deliver the greatest care possible. They highlighted the critical need for caregivers to have their own support networks and health professionals’ constant guidance in the process. However, the chances of participants being not a most representative sample and the lack of caregivers of an individual with severe dysphagia posed the major limitations of this study.

2.7.9 Research Gap

The above studies provide an overview of caregiver burden in caregivers of individuals with dysphagia associated with heterogeneous etiologies. There are a few studies mentioned above that elucidate their expectations from healthcare professionals, studies that highlight third-party disability among caregivers of dysphagics, and studies that explicate the caregiver's quality of life and ways to improve it. Over several decades, with an increasing prevalence of dysphagia, many studies have been conducted to explore the burden experienced by caregivers of individuals with dysphagia. However, very few tools have been developed to date to quantify the same. A recently developed self-assessment tool to assess the dysphagia-specific caregiver burden, the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES; Shune & Namasivayam-MacDonald, 2020) questionnaire, is in the Western context and pertains to their culture. Nevertheless, there are no such screening tools in the Indian context, particularly in Malayalam. Up until recently, an elaborate questionnaire was developed by Jain and Jagtap in 2021 in Marathi, which assesses the quality of life of the caregivers of adults with dysphagia. Apart from this recent advancement, no other tool is available in the Indian context in any other language that focuses on the burden of caregivers caring for individuals with dysphagia. The dysphagia management requiring to be a multidisciplinary one, with the caregiver being a prime part of it, necessitates the caregiver’s needs and well-being to be concentrated in the management plan. Hence, there is a dire need for tools that could identify dysphagia-specific burden, the use of which could improve the caregiver’s and their care recipient’s quality of life.

Chapter III

Method

The current study aimed to trans-adapt the CARES screening tool in Malayalam and validate the tool on caregivers of individuals with dysphagia. The primary objectives of the study were to adapt and translate the caregiver burden screening tool CARES to Malayalam and to determine the validity (content and construct validity) and reliability (test-retest reliability) of the constructed Malayalam version-CARES screening tool on carers of individuals with dysphagia. 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 cause of dysphagia, dependency status, feeding status, and duration of use of tube feeding) variables and the scores on Malayalam version of the CARES tool.

3.1 Research Design

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

3.2 Ethical Considerations

The study was conducted in accordance with the ethical standards for Biobehavioral 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 (Appendix A).

3.3 Tool Development and Testing

The study carried out was conducted in four phases:

Phase 1: Seeking Permission from the Original Authors Prior to Trans-Adaptation

of the CARES Questionnaire

In the initial step of the study, consent was obtained from the original authors, who developed the CARES screening tool (Appendix B), to translate, modify and adapt the tool as required. This was done before the translation and adaptation of the questionnaire.

Phase 2: Adaptation

Adaptation consisted of reviewing, revising, and appropriately adapting the CARES screening tool. The questions or terms that were not understandable or acceptable culturally and socially were replaced by more relevant and understandable questions/phrases by three experienced Speech-Language Pathologists (SLPs) with a minimum of 3 years of experience in dysphagia. For example, the term “Heimlich” was elaborated and presented in a better comprehensible manner.

Phase 3: Translation of CARES from English to Malayalam

The original version of the CARES (Shune et al., 2020) questionnaire was translated into Malayalam, complying with the standard WHO guidelines for the translation and adaptation of tools. The given steps were followed in this study:

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

Step 1. Forward Translation. The CARES questionnaire was translated from English "source" to Malayalam"target". The forward translation was performed by two SLPs who had Malayalam as their native language and English as theirsecond language. Translators were instructed to aim at the conceptual equivalent of the phrase, not a literal translation, i.e., not a word-for-word translation. They were notified to focus on the meaning of the original term/phrase and 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.
- Avoid lengthy sentences with numerous clauses.
- 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 main focus.
- Translators should consider age and gender issues of applicability and avoid terminology that may be offensive to the target group.

The forward-translated questionnaire was sent to a panel of experts for review.

Step 2. Expert Panel Review. A panel of four bilingual individuals fluent in English and Malayalam was constituted for the questionnaire review. The expert panel members included three SLPs who had a minimum of 3 years of clinical experience with dysphagia and were fluent in both Malayalam and English, along with an individual who was proficient in Malayalam. This stage aimed to recognize vague statements/concepts in the translation and to sort out any disparities between the forward translation and existing cross versions of the questions, if any. 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 1, 4, 6, 7, 9, and 10 in Part A and for statements 2, 3, 4, 5, 6, 8, 9, 10, 11 and 13 in Part B, for example, the term “/saːd̪ʱanaŋŋaɭ/” was changed to “/bʱakʂaɳa pad̪aːrt̪t̪ʰaŋŋaɭum paːniːjaŋŋaɭum/”, the phrase “/bud̪d̪ʱimuʈʈukaɭ paɾiɦaɾikkaːn aʋarkkə kaɻijun̪n̪at̪rajum t͡ʃejjun̪n̪illen̪n̪ə/” was changed to “/bud̪d̪ʱimuʈʈukaɭ paɾiɦaɾikkun̪n̪at̪inaːji aʋarkkə kaɻijun̪n̪at̪rajum ʃramikkun̪n̪illa en̪n̪ə/”, insertion of the term “/ɲaːn/” in statement 4 etc. The other SLP suggested the addition of examples befitting to our culture along with certain statements (such as examples for statements 6 and 8 in Part A) 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.

Step 3. Backward Translation. Using the same method described in the initial step, another independent translator, who was not knowledgeable of the questionnaire, translated the tool back from Malayalam "target" to English "source". Like in the initial translation, the focus in the reverse translation was not on linguistic equivalence but on conceptual and cultural equivalence. The discrepancies noted in the previous steps were discussed with the participants involved in the earlier steps. The necessary modifications were made as required till a generally acceptable version was obtained. The SLP was able to translate the questionnaire back to the original version with retained conceptual equivalence.

Step 4. Pretesting and Cognitive Interviewing. A pretest was conducted on five participants of the target population, i.e., five primary caregivers of individuals with dysphagia. The inclusion and exclusion criteria for selecting participants in this step were the same as those for the validation stage. The questionnaire was handed to the participants, who were asked to read, understand and interpret the questions. Respondents suggested more understandable sentences or words compatible with their realities and culture if there were unclear or inappropriate words and questions. The suggestions made were to change the word “/n̪aːɳakkeːʈə/” due to inappropriateness and rephrase statement 3 in Part B due to reduced clarity. The respondents reported that a few statements in Part B were redundant or similar, such as statements 8, 9, 10 and 12, which discussed the care recipient’s feelings and emotions (i.e., depression, stress, anxiety and worry. Respondents returned the proposed modifications in the pretest to the experts. The changes were incorporated, after which the questionnaire was finalised. English terms (depressed, stressed, and anxious) of the affective expressions (/ʋiʂaːd̪am/, /maːnasika sammard̪d̪am/, and /ut̪kaɳʈʰa/) were added in statements 8, 9 and 10 in Part B to improve comprehension, and the final translated version of the screening tool was prepared.

Step 5. Final Version. The amended final version of the questionnaire in Malayalam was prepared after incorporating all the suggestions put forth by the reviewers.

Phase 4: 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 specialized in dysphagia were asked to evaluate the translated screening tool. They were asked to rate the items on a three-point Likert scale regarding ambiguity, transparency, culturalappropriateness, and representativeness (Table 3.1).

Table 3.1

Content validation parameters and the rating scale given to the SLPs (n=3)

Parameters	Rating scale		
	1	2	3
Ambiguity	Doubtful	Item needs some revision	Not doubtful, Meaning is clear
Cultural Appropriateness	Inappropriate	Item needs some revision	Highly appropriate
Clarity	Not clear	Item needs some revision	Very clear
Representativeness	Not a representativeof the desired content	Item needs some revision	Highly representative

In addition, around three primary caregivers of individuals with dysphagia were included in determining the comprehensibility, clarity, and relevance of the translated version of the tool. They also rated the items on a three-point Likert scale based on the above-mentioned parameters (Table 3.2).

Table 3.2

Content validation parameters and the rating scale given to the primary caregivers (n=3)

Parameters	Rating scale		
	1	2	3
Comprehensibility	Not understandable	Understandable, but the item needs some revision	Understandable and Meaning is clear
Clarity	Not clear	Clear, but the item needs some revision	Very clear
Relevance	Not Relevant	Relevant, but the item needs some revision	Highly representative

The necessary changes in terms of changing words, rephrasing sentences that were deemed inappropriate or unclear, and adding additional items were made, for example, the term "/ʋijoːɟikkaːruɳʈə/" was changed to "/joːɟikkaːrilla/", addition of a few examples of the situation intended through statement 8, such as "/ud̪aː, ʈrippə poːkun̪n̪at̪ə, ʂoːppimgə poːkun̪n̪at̪ə, kuʈumba samgamam en̪n̪iʋa/", etc. A modified final translated version of the screening tool was prepared after incorporating all the suggested changes and was used for the pilot study (Appendix C).

Step 2. Pilot Study. Five primary caregivers of individuals with dysphagia 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 time taken and any challenges faced during the filling up of the questionnaire were analyzed. The participants were able to fill out the translated tool within 5 to 10 minutes, were able to understand the questionnaire and provide appropriate responses.

Step 3. Data Collection. Following the pilot study, data collection was carried out on the primary caregivers of individuals with dysphagia.

Participants. As a part of establishing clinical validity, the final adapted questionnaire was administered to the primary caregivers of individuals with dysphagia. The participants for the current study were recruited from various speech and hearing centres, palliative care centres, and rehabilitation centres and through home visits in Kerala, India. Those participants receiving home care were only selected. The primary caregivers who visited these centres for follow-ups or consultations were recruited for the study with their informed consent. Primary caregivers (male/female; informal caregiver) of individuals aged 18 years and above with dysphagia associated with different etiologies (malignancy, TBI, CVA, Brain tumour, Parkinson’s disorder) were recruited for the study. The care recipient's swallowing issues were identified based on the information in the case file stating ‘swallowing difficulties present in the patient’ following interaction with the caregiver regarding the same. The caregivers were required to be 18 years of age or above and should be providing caregiving services for at least one month. The caregivers were required to be able to read and understand Malayalam. 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 caregivers assisted by home nurses were also 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:8, female:52) with a mean age of 51.23 years (males: 48±13.74 years, females: 51.73±11.96 years) completed the questionnaires. The demographic details of the participant caregivers and their care recipients are given in Table 3.3 & 3.4.

Table 3.3

Demographic details of the participant caregivers (N=60)

Demographic data	*M*±*SD*	Number of participants (*n*)
Age (in years)		
Overall	51.23±12.15	
Male	48.00±13.74	
Female	51.73±11.96	
Gender		
Male		8
Female		52
Relationship with the care recipient		
Spouse		36
Children		14
Mother		6
Others (sister, daughter-in-law)		4 (1, 3)
Duration of caregiving services		
12 months or less		46
More than 12 months		14
Socioeconomic status		
Upper lower		27
Lower middle		26
Upper middle		7

Note. M and *SD* represent mean and standard deviation, respectively.

Table 3.4

Demographic details of the care recipients

Demographic data	*M*±*SD* (in years)	Number of care recipients (*n*)
Age		
Overall	60.23±13.33	
Male	58.16±13.38	
Female	65.47±12.04	
Gender		
Male		43
Female		17
Etiology of dysphagia		
Cancer (CA)*		32
TBI		7
CVA		16
Others (Brain tumor, Parkinson’s disease)		5 (3, 2)
Dependency status		
Dependent		31
Independent		29
Feeding status		
Nonoral intake		19
Oral intake		41
Duration of tube feeding		
3 months or less		10
More than 3 months		9

Note. M and *SD* represent mean and standard deviation, respectively.

CA includes cancer of the oral cavity, tongue, floor of the mouth, buccal mucosa, oropharynx, pharynx, larynx, esophagus, stomach etc.

Step 4. Construct Validity. Construct validity was established by administering the Functional Oral Intake Scale (FOIS, Crary et al., 2005) and the Malayalam version of the Caregiver Burden Assessment Scale (CBAS, Arsha, 2020). The FOIS assesses the functional oral intake level of an individual with swallowing difficulties, which gives an indirect measure of observer-rated severity of an individual's dysphagia. This was done based on the assumption that the caregiver burden correlated with the care recipient's dysphagia severity. FOIS is a valid 7-item scale that is classified into 7 levels. All the levels in the scale focus on the patient's oral intake on a daily basis, with levels 1 to 3 indicating different degrees of nonoral feeding and levels 4 to 7 indicating different degrees of oral feeding alone, without nonoral supplementation. Table 3.5 shows the number of care recipients falling under different FOIS levels.

Table 3.5

Number of care recipients falling under different levels of FOIS

FOIS Level	Number of patients, *n*
Level 1	8
Level 2	7
Level 3	4
Level 4	6
Level 5	21
Level 6	14

In addition, the Malayalam version of the CBAS was administered with the assumption that the caregivers experiencing a greater burden specific to dysphagia might also exhibit a greater general burden. The Malayalam version-CBAS is a valid and reliable 9-item instrument with two subscales named “consequences of caregiving” (subscale 1), having 5 items, and “lack of financial security” (subscale 2), consisting of 4 items. It assesses the burden of caregiving for patients with serious health issues aided by the palliative care program in Kerala. This self-administered tool helps rate the items on a 4-point Likert-type scaleranging from 0 to 3 (0:strongly disagree to 3:strongly agree). The number of caregivers who experience low, moderate and high burden under each subscale and total scale of the Malayalam version-CBAS is depicted in Table 3.6.

Table 3.6

Responses for Malayalam version CBAS.

Severity	Total scale	Subscale 1	Subscale 2
Low	13	12	17
Moderate	38	46	33
High	9	2	10

Note. This table shows the severity of the burden experienced by the caregivers (low, moderate, high) given in the total scale and when subscale 1 and subscale 2 are considered.

3.4 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 form, the Malayalam version of the CARES questionnaire, the Malayalam version of the CBAS questionnaire, and the FOIS. The participants filled out the other forms besides the demographic form and the FOIS. The participants were explained about the identity anonymous policy and withdrawal anytime during the study option. The participants' written consent was collected after explaining the purpose and details of the study. The demographic data of the participants concerning the caregiver's and care recipient's age, caregiver's and care recipient's gender, caregiver's relationship with the care recipient, duration of the caregiving services, other medical complications of caregiver and care recipient, caregiver education, care recipient dependency status, socioeconomic status, care recipient feeding status (nonoral intake/oral intake), and duration of tube feeding were collected and detailed in the demographic form by the author. The modified Kuppuswamy socioeconomic scale (Sood & Bindra, 2022) was used to classify the caregivers and care recipients into different levels of socioeconomic status (SES). The author administered FOIS to assess the care recipient's oral feeding status and indirect dysphagia severity index. The adapted questionnaire (Malayalam version-CARES) and the Malayalam version-CBAS questionnaire were provided to the target group to fill in. The participants were also instructed to mention the statement number in the allocated space under each subscale of the adapted questionnaire, which was perceived to be the most burdensome. A total of 10-15 minutes were taken for the forms to be filled out by the participants.

3.5 Test-Retest Reliability

The test-retest reliability was conducted on about 10% (*n*=6) of the participants after 2 weeks of completion of the initial data collection. The same translated Malayalam version of the CARES questionnaire was administered again to a few of the randomly selected participants (*n*=6) after getting their consent. The participants were explained the rationale behind doing the same and were requested for their sincere cooperation. They were called a few days after the initial data collection and enquired about their willingness to re-administer the questionnaire after two weeks. The willing participants were given the forms to fill out once again and instructed to return them after completion. The obtained responses were compared with the initial responses and then checked for statistically significant correlation or discrepancy between the test and retest results.

3.6 Statistical Analysis

The total scores of the Malayalam version of the CARES (subscores and total score) and the Malayalam version-CBAS 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 tests was done prior to the conduction of any statistical analysis. Descriptive statistics was computed for the total scores and the scores of Part A and Part B of CARES. The construct validity was determined using Spearman’s rank-order correlation. Test-retest reliability or internal consistency analysis was done by calculating Cronbach’s alpha. The participant (caregiver) and their care recipient variables were analysed for their influence on the dysphagia-specific caregiver burden 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 CARES screening tool in Malayalam and validate the tool on caregivers of individuals with dysphagia. The other objectives of the study were to check for any association between different caregiver and care recipient independent variables, such as caregiver's age, caregiver's gender, caregiver's relationship with the care recipient, duration of the caregiving services, other medical complications of caregiver and care recipient, socioeconomic status, care recipient dependency status, care recipient feeding status, and duration of tube feeding, with the Malayalam version of the CARES scores.

The tool was adapted by three experienced SLPs specialized in deglutition and then translated by a total of 7 SLPs and 5 primary caregivers who carried out different steps in the translation process in separate groups. The content validation of the current study was performed by three SLPs specialized in deglutition and three primary caregivers of individuals with dysphagia with adequate proficiency in Malayalam. CARES was administered to 60 primary caregivers of individuals with dysphagia. FOIS and the Malayalam version-CBAS were administered to assess the construct validity.

The total and subscale scores of the Malayalam version of the CARES and data on all other independent variables obtained were tabulated and entered into the SPSS software (version 26) for statistical analysis. Descriptive statistics was computed for the total scores and the scores of Part A and Part B of the adapted CARES tool. Spearman's rho correlation coefficient was computed to verify the assumption that greater dysphagia-specific caregiver burden was associated with more severe swallowing issues established using the FOIS tool and with more general caregiver burden scores measured using the Malayalam version-CBAS. The FOIS gives the oral intake status of a patient with dysphagia, which can also be considered an indirect measure of the severity of dysphagia.

To assess the effect of different caregiver and care recipient variables on the dysphagia-specific caregiver burden, each participant's total and subscale scores of the Malayalam version of the CARES were compared or correlated with the data obtained for these variables using appropriate statistical methods. The Shapiro-Wilk test performed revealed the collected data to be non-normally distributed. Hence, nonparametric tests, Kruskal-Wallis and Mann-Whitney U tests were performed accordingly, depending on the number of categories under each independent variable, to analyze the association between the dependent variable (total and subscale scores of the adapted CARES tool) 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 dysphagia-specific caregiver burden. The results of the current study have been described in the sections below.

Test-retest reliability was also assessed on 10% of the participants (n=6) after two weeks of initial data collection. Test-retest reliability or internal consistency analysis was done by calculating Cronbach’s alpha. Generally, a correlation coefficient or an alpha coefficient of ≥0.70 is considered to be reliable.

4.1 Performance on the Trans-Adapted CARES Tool

Descriptive statistics was computed for the total scores and the scores of Part A and Part B of CARES. The mean (*M*) and standard deviation (*SD*) for the total scores on the Malayalam version-CARES was 14.52±5.31. The mean and *SD* for Part A (subscale 1 scores) was 6.32±2.31, and for Part B (subscale 2 scores) was 8.20±3.44. Part A is assessed for the behavioral and functional changes in the caregiver, while Part B is assessed for the subjective caregiver stress. The mean scores suggest that the primary caregivers of individuals with dysphagia experience a considerable degree of burden in terms of behavioral and functional changes or the perceived stresses as a consequence of their dysphagia-related caregiving.

4.2 Performance on Each Statement in the Trans-Adapted CARES Tool

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

Table 4.1

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

Statements	Part A*		Part B	
	Yes	No	Yes	No
	n (%)	*n* (%)	*n* (%)	*n* (%)
Statement 1	50 (83.33)	10 (16.67)	25 (41.67)	35 (58.33)
Statement 2	54 (90)	6 (10)	39 (65)	21 (35)
Statement 3	49 (81.67)	11 (18.33)	20 (33.33)	40 (66.67)
Statement 4	11 (18.33)	49 (81.67)	51 (85)	9 (15)
Statement 5	44 (73.33)	16 (26.67)	35 (58.33)	25 (41.67)
Statement 6	38 (63.33)	22 (36.67)	36 (60)	24 (40)
Statement 7	41 (68.33)	19 (31.67)	38 (63.33)	22 (36.67)
Statement 8	35 (58.33)	25 (41.67)	24 (40)	36 (60)
Statement 9**	40 (66.67)	13 (21.67)	41 (68.33)	19 (31.67)
Statement 10	17 (28.33)	43 (71.67)	47 (78.33)	13 (21.67)
Statement 11	-	-	52 (86.67)	8 (13.33)
Statement 12	-	-	58 (96.67)	2 (3.33)
Statement 13	-	-	28 (46.67)	32 (53.33)
Statement 14	-	-	11 (18.33)	49 (81.67)
Statement 15	-	-	12 (20)	48 (80)
Statement 16	-	-	19 (31.67)	41 (68.33)

*PART A has only 10 statements

** For statement 9 in Part A, the remaining 7 participants have responded with N/A.

In Part A, a maximum percentage of the participants responded in affirmation to statement 2 (*n*=54, 90%). This statement was about the increased "mealtime- and nutrition-related responsibilities". Statements 1 and 3 received the highest affirmations following statement 2 (*n*=50, 83.33%; *n*=49, 81.67%), which reflects the increased time utilization for mealtimes and nutrition-related expenditures experienced by the caregiver. The lowest percentage of responses was obtained for statement 4 (*n*=11, 18.33%), which reported disagreement with other family members regarding the management of the care recipient's swallowing difficulties. A few (*n*=7, 11.67%) of the participants reported the situation of "going out to eat" to be not applicable to them (statement 9) since they never had the particular habit before to experience it as a change post-care recipient's condition.

In Part B, the highest affirmatory response was obtained for statement 12 (*n*=58, 96.67%), which reported "caregiver's worry about the way care recipients feel regarding their swallowing issues", and the lowest for statement 11, which states the scenario of "feeling embarrassed around others because of the care recipient's swallowing problems" as a result of managing their care recipient's swallowing issues. Other statements reporting "fear of choking" and "anxiety" (statements 4 and 10, respectively) with respect to the care recipient's swallowing difficulties also received high affirmatory responses from the caregivers, while statements reporting "feeling isolated from family and friends" and "feeling trapped as a result of managing the loved one's swallowing issues" (statements 14 and 15, respectively) had a low affirmation.

4.3 Participant Responses for the Most Burdensome Statements

From the responses of the participants, the statement 2 regarding the increased mealtime- and nutrition-related responsibilities was the most burdensome in

Part A, as reported by the caregivers (*n*=32, 53.33%). Statement 2 was followed by statements 5, 3, and 1 (*n*=26, 43.33%; *n*=24, 40%; *n*=17, 28.33%), which state about the interferences in the caregivers' day-to-day routine activities, modified nutrition-related increased expenses, and increased time utilization for mealtimes as a consequence of their loved one's swallowing issues.

In Part B, the most burdensome issue experienced by the caregivers was identified as statement 4 (*n*=29, 48.33%), which stated the caregiver's fear of choking, followed by statements 10, 6, 9, 2, 16, and 8 (*n*=14, 23.33%; *n*=13, 21.67%, *n*=13, 21.67%, *n*=9, 15%; *n*=8, 13.33%; *n*=7, 11.67%). These statements reflected the caregiver's emotional burden (such as anxiety, stress, and depression about their loved one's swallowing issues and worry concerning the improvement of their swallowing issues), their insufficient time to consider their own physical health and their difficulty with ensuring adequate nutritious diet for the care recipient.

4.4 Construct Validation of the Trans-Adapted CARES

The construct validity of the Malayalam version of the CARES tool was done by correlating the total scores of the translated tool with the different Functional Oral Intake Scale (FOIS) levels and with the total scores of the Malayalam version of the Caregiver Burden Assessment Scale (Malayalam version-CBAS). Spearman's Rank Order Correlation was administered for the same purpose. The results of the analysis revealed a statistically significant negative strong correlation between the Malayalam version of the CARES total, subscale 1 and subscale 2 scores and the FOIS levels, with a correlation coefficient of -0.69 (*p*=0.00), -0.69 (*p*=0.00) and -0.60 (*p*=0.00), respectively (Table 4.2). As the FOIS level increased, the CARES scores (total and subscale scores) decreased. This indicated that the dysphagia-specific caregiver burden is found to decrease with improvement in the care recipient's oral intake.

The total, subscale 1, and subscale 2 scores of the Malayalam version of the CARES also correlated with the total scores of the Malayalam version-CBAS, yielding a correlation coefficient of 0.67 (*p*=0.00), 0.67 (*p*=0.00), and 0.61 (*p*=0.00), respectively, suggestive of a strong positive correlation (Table 4.2). These results indicate a greater perceived dysphagia-specific caregiver burden correlated with a perceived greater general caregiver burden.

Table 4.2

Results of Spearman's Rank Order correlation between the CARES total, subscale 1, and subscale 2 scores and the FOIS levels and the Malayalam version-CBAS scores (N=60)

CARES section	FOIS		Malayalam version-CBAS	
	Correlation coefficient, *r*	*p*-value	Correlation coefficient, *r*	*p*-value
Subscale 1	-0.69	0.00*	0.67	0.00*
Subscale 2	-0.60	0.00*	0.61	0.00*
Total	-0.69	0.00*	0.67	0.00*

Note. Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

* p<0.01.

4.5 Test-Retest Reliability Analysis

The trans-adapted CARES tool was readministered on 10% of the total participants (6 participants) 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 subscale scores and the total scores of the tool. The correlation coefficient was found to be 1.00, 0.986, and 1.00 for subscale 1, subscale 2 and total scores, respectively. The Cronbach's Alpha was found to be 1.00, 0.99, and 0.99 for Part A, Part B and total scale, revealing a good internal consistency among items.

4.6 Association Between the Trans-Adapted CARES Tool 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 CARES tool and different caregiver variables (such as age and duration of caregiving) and care recipient variables (such as duration of tube feeding) due to the data being continuous and not a grouped one. Whereas comparison analysis across groups was performed to identify the association between the total and subscale scores of the trans-adapted CARES tool and different caregiver variables (such as gender, relationship with the care recipient, and socioeconomic status) and care recipient variable (such as etiology of dysphagia, feeding status, and dependency status). The results of the analysis performed are given below.

4.6.1 Correlation Between the Caregiver Age and the CARES Scores

The total and subscale scores of the CARES 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 ($p > 0.05$) across total scores and subscale scores (Table 4.3). The correlation coefficient for subscale 1, subscale 2 and total scores were -0.075 (p=0.57), 0.143 (p=0.28), and 0.094 (p=0.48), respectively. The findings suggest no correlation between the age of the caregiver and the dysphagia-specific caregiver burden experienced by the caregiver. There was no effect of the caregiver's age on the experienced behavioral and functional changes and perceived stresses or burdens as a result of their caregiving to individuals with dysphagia. The burden was experienced by all caregivers of individuals with dysphagia, irrespective of their age.

Table 4.3

Results of Spearman's Rank Order correlation between the caregiver age and the CARES scores (N=60)

CARES section	Correlation coefficient, *r*	*p*-value
Subscale 1	-0.075	0.57
Subscale 2	0.143	0.28
Total	0.094	0.48

Note. Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

4.6.2 Comparison of CARES Scores Across Gender

The caregiver participants were categorized into two groups: males and females. A descriptive statistical analysis was done, and the mean and standard deviation were computed (Table 4.4). The mean scores for the perceived burden were slightly high for the females. Mann-Whitney U test was performed to compare the mean of CARES scores (total and subscale scores) across the genders. The results revealed no statistically significant difference in the subscale and total scores of the adapted CARES tool ($/Z/=0.41$, $p=0.68$ for subscale 1 scores; $/Z/=1.04$, $p=0.29$ for subscale 2 scores; $/Z/=0.72$, $p=0.47$ for total scores) between males and females (Table 4.4). The results suggest that dysphagia-specific caregiver burden, even though was more experienced by females, was not statistically significant.

Table 4.4

Mean, standard deviation and results of Mann-Whitney U test of CARES scores across gender (N=60)

CARES section	*M*±*SD*		/Z/	*p*-value
	Male	Female		
Subscale 1	6.13±2.36	6.35±2.33	0.41	0.68
Subscale 2	6.88±4.22	8.40±3.31	1.04	0.29
Total	13.00±6.23	14.75±5.19	0.72	0.47

Note. M and *SD* represent mean and standard deviation, respectively.

Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

4.6.3 Comparison of CARES Scores Across Caregiver Relationship Status

The caregivers included spouses, children, mother, daughter-in-law and sister of the patient with dysphagia. The participants were grouped into four categories, namely spouses (*n*=36), children (*n*=14), mothers (*n*=6) and others (*n*=4). Due to the limited number of participants who were daughters-in-law or sisters, they were categorized under “others”. Descriptive statistical analysis was done for the obtained data. The mean and standard deviation for the CARES scores (total and subscale scores) across each relationship status are given in Table 4.5. The Kruskal-Wallis test revealed no statistically significant difference in the scores (total as well as subscale scores) of the Malayalam version-CARES across different categories of relationship status. The chi-square values were found to be 1.35 (*p*=0.72), 4.76 (*p*=0.19), and 3.41 (*p*=0.33) with 3 degrees of freedom for subscale 1, subscale 2 and total scores. The findings suggest that even though spouses were found to experience a slightly greater burden, there was no statistically significant difference between the Malayalam version-CARES scores across different relationship statuses. Hence, irrespective of the type of relation of the primary caregiver with their care recipient, there was no significant difference in the dysphagia-specific caregiver burden experienced by them. They were found to experience behavioral and functional changes and stresses in a similar way. The results of the Kruskal-Wallis test across different caregiver relationships are given in Table 4.5.

Table 4.5

Mean, standard deviation and results of the Kruskal-Wallis test for the CARES score across different caregiver relationships (N=60)

CARES section	*M* (*SD*)				Test statistics, χ^2	Degrees of freedom	*p*-value
	Spouse	Children	Mother	Others			
Subscale 1	6.56 (2.24)	5.71 (2.61)	6.33 (2.66)	6.25 (1.71)	1.35	3	0.72
Subscale 2	8.94 (3.46)	6.50 (3.61)	7.67 (2.88)	8.25 (1.50)	4.76	3	0.19
Total	15.50 (5.24)	12.21 (5.82)	14.00 (5.33)	14.50 (1.91)	3.41	3	0.33

Note. M and *SD* represent mean and standard deviation, respectively.

Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

4.6.4 Correlation Between the Duration of Caregiving Services and the CARES Scores

The total and subscale scores of the Malayalam version-CARES were calculated for each participant and subjected to correlational analysis across different durations of caregiving. Spearman's Rho was calculated to identify the correlation between the two variables. The results obtained by correlating caregiving duration with the Malayalam version-CARES revealed a significant negative correlation, albeit low, with a *p*-value less than 0.05 between subscale 1 and total score and caregiving duration (r=-0.27, p=0.04; r=-0.27, p=0.04), as shown in Table 4.6. This suggests that the caregivers experience slightly more perceivable changes in their behavioral and functional aspects of life as a result of caregiving for individuals with dysphagia when the caregiving duration is less, resulting in a greater dysphagia-related burden experienced by the carers. The dysphagia-related burden tends to gradually reduce as the caregiving duration increases.

Table 4.6

Results of Spearman's Rank Order correlation between the duration of caregiving and the CARES scores (N=60)

CARES section	Correlation coefficient, *r*	*p*-value
Subscale 1	-0.27	0.04*
Subscale 2	-0.22	0.09
Total	-0.27	0.04*

Note. Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

*$p<0.05$.

4.6.5 Comparison of CARES 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). The data collected only included participants falling under upper lower (UL), lower middle (LM), and upper middle (UM). There were 27 participants under UL, 26 under LM and 7 under UM. The results of descriptive statistical analysis are given in Table 4.7. The Kruskal-Wallis test was done to determine any significant difference between the CARES scores (subscale scores and total) across different levels of SES. The chi-square values were found to be 2.44 (p=0.30), 2.19 (p=0.33), and 1.84 (p=0.40) with 2 degrees of freedom for subscale 1, subscale 2 and total scores (Table 4.7). The test results revealed no significant difference between the CARES scores across different levels of SES. However, a slightly greater burden was observed for the upper-lower group among the three SES groups based on mean, even though it was not statistically significant.

Table 4.7

Mean, standard deviation and results of the Kruskal-Wallis test for the CARES scores across different SES (N=60)

CARES section	*M* (*SD*)			Test statistics, χ^2	Degrees of freedom	*p*-value
	Upper lower	Lower middle	Upper middle			
Subscale 1	6.63 (2.42)	5.92 (2.15)	6.57 (2.57)	2.44	2	0.30
Subscale 2	8.96 (3.06)	7.65 (3.83)	7.29 (3.20)	2.19	2	0.33
Total	15.59 (5.09)	13.58 (5.51)	13.86 (5.37)	1.84	2	0.40

Note. M and *SD* represent mean and standard deviation, respectively.

Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

4.6.6 Comparison Between the Etiology of Dysphagia and the CARES Scores

Dysphagia etiologies in the care recipients were categorized into four groups, namely, cancer (CA) of structures involved in swallowing (*n*=32), TBI (*n*=7), CVA (*n*=16), and others (*n*=5) which include brain tumor and Parkinson's disease. The tabulated data of the same was subjected to the nonparametric test, the Kruskal-Wallis test, after doing descriptive statistical analysis. The different causes of dysphagia and the CARES scores were compared. The chi-square values were found to be 2.08

(*p*=0.56), 1.78 (*p*=0.62), and 1.54 (*p*=0.67) with 3 degrees of freedom for subscale 1, subscale 2 and total scores. Hence, the analysis results revealed no significant difference in the Malayalam version-CARES scores (total and subscale scores) across various etiologies of dysphagia. This indicated that the caregiver experienced dysphagia-specific caregiver burden was independent of the cause of dysphagia. The results for the subscale items and total items across different etiologies are given in Table 4.8.

Table 4.8

Mean, standard deviation and results of the Kruskal-Wallis test for the CARES scores across different etiologies of dysphagia (N=60)

CARES section	*M* (*SD*)				Test statistics, χ^2	Degrees of freedom	*p*-value
	CA	TBI	CVA	Others			
Subscale 1	6.06 (2.31)	7.29 (2.63)	6.31 (2.41)	6.60 (1.67)	2.08	3	0.56
Subscale 2	8.28 (3.35)	9.14 (4.22)	7.31 (3.42)	9.20 (3.35)	1.78	3	0.62
Total	14.34 (5.26)	16.43 (6.53)	13.63 (5.23)	15.80 (4.87)	1.54	3	0.67

Note. M and *SD* represent mean and standard deviation, respectively.

Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

4.6.7 Comparison Between the Care Recipient Feeding Status and the CARES Scores

The care recipients were divided into two groups depending on their feeding status: nonoral intake and oral intake group. There were 19 care recipients dependent on tube feeding (nonoral intake) and 41 care recipients on oral intake. Descriptive statistical analysis was carried out along with the Mann-Whitney U test since the data followed a non-normal distribution. The descriptive statistical analysis results are presented in Table 4.9. The results of the Mann-Whitney U test (Table 4.9) revealed a statistically significant difference between the two categories of care recipient feeding status since the *p*-value was less than 0.05 (/*Z*/=3.97, *p*=0.00 for subscale 1 scores, /*Z*/=2.68, *p*=0.01 for subscale 2 scores; and /*Z*/=3.49, *p*=0.00 for total scores). The findings suggested that care recipients with nonoral intake contribute more to the caregivers' experienced burden (greater mean value of subscale and total scores in nonoral intake). Effect size calculation was done. It was found to be 0.51, 0.35, and 0.45 for subscale 1, subscale 2 and total score, signifying a large, medium, and medium effect, respectively.

Table 4.9

Mean, standard deviation and results of the Mann-Whitney U test for the CARES scores across different categories of care recipient feeding status (N=60)

CARES section	*M*±*SD*		/*Z*/	*p*-value
	Oral	Non-oral		
Subscale 1	5.54±2.38	8.00±0.75	3.97	0.00*
Subscale 2	7.46±3.62	9.79±2.42	2.68	0.01*
Total	13.00±5.53	17.79±2.82	3.49	0.00*

Note. M and *SD* represent mean and standard deviation, respectively.

Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

*$p<0.05$.

4.6.8 Comparison Between the Care Recipient Dependency Status and the CARES Scores

The care recipients are divided into two groups, the dependent group and the independent group, based on their dependency on caregivers for self-help skills, including feeding. The care recipients who were not capable of self-care and depended on the caregiver for daily activities and feeding were grouped under the dependent group (*n*=31), while the independent group included care recipients who were capable of self-care and feeding (*n*=29). The Malayalam version-CARES scores were compared between the two categories of care recipient dependency to see if there was an impact on the dysphagia-specific caregiver burden, especially when the individual was dependent on the caregiver for feeding. Descriptive statistical analysis and Mann-Whitney U tests were performed. The results indicated a significant difference in the scores of subscale 1 of the Malayalam version-CARES across both categories of care recipient dependency (/*Z*/=2.93, *p*=0.00). This finding suggests that the care recipients who were not capable of self-care and self-feeding contributed to the behavioral and functional changes in the carer significantly when compared to those who were capable of all self-care. This, in turn, brought a significant difference in the total score of the CARES in the two categories (/*Z*/=2.49, *p*=0.01). The results obtained were suggestive of an overall increase in the dysphagia-specific caregiver burden among caregivers caring for dependent care recipients. This is indicated by an increase in the total scores of the Malayalam version-CARES in the dependent group when compared to the independent group. The statistical analysis results of the tests carried out are given in Table 4.10. The effect size was found to be 0.38 and 0.32 for subscale 1 and total scores, respectively, signifying a medium effect.

Table 4.10

Mean, standard deviation and results of Mann-Whitney U test for the CARES scores across different categories of care recipient status (N=60)

CARES section	*M*±*SD*		/*Z*/	*p*-value
	Independent	Dependent		
Subscale 1	5.38±2.41	7.19±1.85	2.93	0.003*
Subscale 2	7.45±3.43	8.90±3.36	1.59	0.112
Total	12.83±5.38	16.09±4.81	2.49	0.013*

Note. M and *SD* represent mean and standard deviation, respectively.

Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2- scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

*$p<0.05$.

4.6.9 Correlation Between the Duration of Tube Feeding and the CARES Scores

The total and subscale scores of the CARES of care recipients dependent on tube feeding were subjected to correlational analysis (Spearman's Rank Order correlation) across the duration of tube feeding. The results obtained revealed that the correlation between the duration of tube feeding and the Malayalam version-CARES scores was not significant since the *p*-value was greater than 0.05 across all the categories for subscale 1 (r=0.04, p=0.86), subscale 2 (r=-0.03, p=0.91) and total scores (r=0.03, p=0.91). The results are given in Table 4.11.

Table 4.11

Results of Spearman's Rank Order correlation between the duration of tube feeding and the CARES scores (N=19)

CARES section	Correlation coefficient, *r*	*p*-value
Subscale 1	0.04	0.86
Subscale 2	-0.03	0.91
Total	0.03	0.91

Note. Subscale 1- scores of Part A of the Malayalam version-CARES; Subscale 2 – scores of Part B of the Malayalam version-CARES; Total- total score by adding subscale 1 and subscale 2 scores.

To summarize the findings obtained, a CARES tool was translated, adapted and validated for its contents. The tool was administered to 60 caregivers of persons with dysphagia, and the results revealed that they experienced a considerable degree of dysphagia-specific caregiver burden. Construct validity was determined using Spearman's rho, where a negative correlation was revealed between FOIS level and the Malayalam version-CARES scores, indicating dysphagia-related caregiver burden reduction with increased FOIS levels. A positive correlation was identified between the Malayalam version-CARES scores and Malayalam version-CBAS scores, revealing that an increase in dysphagia-related caregiver burden may indicate an increased general caregiver burden. The results obtained by comparing different caregiver and care recipient variables revealed an association between dysphagia-related caregiver burden and duration of caregiving services, care recipient feeding status, and care recipient dependency status. These findings suggest that caregivers providing dysphagia-specific care for less duration experienced a greater burden, especially with respect to behavioral and functional changes, than those providing care for more duration. The caregiver burden was observed to decrease gradually as the duration of caregiving increased. The individuals who were on nonoral intake and those dependent on caregivers even for feeding were likely to increase the caregivers' burden. The reliability testing revealed good test-retest reliability with correlation coefficients of 1.00, 0.99, and 1.00 for subscale 1, subscale 2 and total scores of the Malayalam version-CARES.

Chapter V

Discussion

Dysphagia is a debilitating condition with a devastating effect on the person with swallowing difficulties and his/her entire family unit. The consequences of dysphagia are not only endured by the patient himself but also by their close ones, especially their informal caregivers. Several studies have reported reduced physical, psychosocial and economical functioning of both the patient and caregivers, drastically reducing their quality of life. The main objectives of the current study were to adapt, translate and validate the CARES screening tool to Malayalam to screen for dysphagia-related burdens of the caregivers in the specific population. The other objectives were to identify any association between different caregiver or care recipient variables and the dysphagia-related burden of the caregiver.

The results of the current study identify the Malayalam version-CARES as a valid and reliable tool to screen for dysphagia-specific caregiver burden among the primary caregivers of individuals with dysphagia. The results of the study are discussed in detail under different sections below.

5.1 Performance of the Primary Caregivers on the Malayalam Version of the CARES

The results revealed that the primary caregivers of persons with dysphagia experienced a considerable degree of dysphagia-specific burden. This is an agreement with several other studies that report that primary caregivers of individuals with dysphagia 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, tube feeding-related activities, reduced support from other closed ones, emotional strain, physical stress, financial difficulties (Coutts & Sayed, 2023; Hassib & Ostia, 2021; Hiatt et al., 2021, 2022; Johansson & Johansson, 2009; Lisiecka et al., 2020; Penner et al., 2012; Rangira et al., 2022; Shune & Namashivayam-MacDonald, 2019).

In the current study, the statements that most participants affirmed in Part A were concerning the increased mealtime- and nutrition-related responsibilities, time utilization for mealtimes and nutrition-related expenditures, while in Part B, the statements about “the caregiver’s worry about the way care recipients feel regarding their swallowing issues”, “fear of choking”, and “anxiety” were identified to be the most reported burdens faced by the caregivers. The least affirmed statements were concerned with the disagreement between the caregiver and other family members regarding the management of the care recipient’s swallowing difficulties (Part A), “feeling embarrassed around others”, “feeling isolated from family and friends”, and “feeling trapped” (Part B) due to the care recipient’s dysphagia.

However, Shune and Namasivayam-MacDonald (2020) reported that maximum participants experienced burden due to increased mealtime duration and inability to perform preferred activities in Part A, while negative emotions like fear with respect to choking and feeling stressed were the maximally agreed to items in Part B by the primary caregivers. “Disagreement from other family members” concerning the dysphagia management, avoidance of food items that could not be consumed by the care recipient (Part A), and care recipient not trying their best to manage their swallowing difficulties (Part B) were the least agreed upon items by the caregivers in the Western context. The discrepancy in these findings may be due to the cultural variability, population type (urban/rural), diverse educational and socioeconomic status between India and Western countries.

5.2 Establishment of Construct Validity of Trans-Adapted CARES Tool

A measure of more general caregiver burden and an indirect indicator of dysphagia severity (functional oral intake level) were used to assess construct validity. The construct validation of the tool, evaluated by performing bivariate correlations (Spearman's rho) between the trans-adapted CARES and the FOIS, and the Malayalam version-CBAS revealed a statistically significant correlation. The dysphagia-specific caregiver burden, as measured by the Malayalam version-CARES scores (Part A, Part B and total scores), was negatively associated with the FOIS and positively associated with the Malayalam version-CBAS, indicating that increased dysphagia-specific caregiver burden has an association with decreased FOIS level and increased general caregiver burden.

This association with FOIS (indirect indicator of dysphagia severity) indicates that better the oral intake of an individual or the less restricted his/her diet is, the lesser is the caregiver burden. Shune et al. (2020) and Suzuki et al. (2022), in their studies, also report a direct correlation between the dysphagia severity and the stresses and burdens experienced by the caregivers. Davis et al. (2021), in their study about the perceived impact of dysphagia on caregivers and care recipients, found an increased experience of burden with increased diet restrictiveness, similar to Shune et al. (2020). Namashivayam-MacDonald and Shune's (2018) findings that worsened feeding behaviours have resulted in increased caregiver burden among elderly care recipients and a "heavy burden" when the care recipients were tube dependent may also be considered supportive of this finding.

Support can also be drawn from other disease conditions. The study conducted by Celik et al. (2022) among caregivers of cancer patients also revealed a higher burden, based on Zarit Burden Interview (ZBI) results, among those caregivers whose care recipients showed greater symptom severity. Similarly, in a study done on caregivers and patients with Alzheimer’s disease by Froelich et al. in 2021, a significant relationship was found between the disease progression and the caregiver burden. A positive correlation was found between the severity of the disease and the increased burden of caregivers based on ZBI scores. These findings show that not only with regard to dysphagia but when other pathological conditions are also considered, a trend can be observed where a progression in the disease course or worsening of disease symptoms tends to increase the caregiver experienced burden. In the current study, the dysphagia severity, irrespective of the underlying disease severity or other caregiver or care recipient variables, was found to solely contribute to the caregiver-experienced increased dysphagia-specific burden. Hassib and Ostia (2021) also report dysphagia as an independent caregiver burden predictor.

The findings of the present study also suggest an increase in dysphagia-related caregiver burden to be associated with an increase in general caregiver burden, which assesses the “consequences of caregiving” and “lack of financial security”. The study done by Shune et al. on the development of CARES in 2020 also suggests a similar finding of the dysphagia-related burden being associated with general caregiver burden when CARES and ZBI scores were correlated. The more severe one’s feeding behaviour or swallowing abilities are, the greater the dysphagia-specific burden has been found. The study by Namashivayam-MacDonald and Shune in 2018 could identify a hike in the general caregiver burden, i.e., an increase in Zarit Burden Scale scores, when the elderly care recipient’s feeding behaviour is exacerbated over time. Several studies on caregiver burden and stresses in the dysphagia population report physical, emotional, social, and financial burdens to be acquainted by the majority of the caregivers, especially informal caregivers, as a consequence of dysphagia management (Coutts & Sayed, 2023; Hassib & Ostia, 2021; Hiatt et al., 2022; Hillege, 2006; Johansson & Johansson, 2009; Lisiecka et al., 2020; Shune & Namashivayam-MacDonald, 2019) which alters their lifestyle and everyday routine and responsibilities contributing to an overall general burden. Dysphagia management by informal caregivers deters them from carrying out their other responsibilities and roles, such as day-to-day activities, household chores, occupational obligations, caring and giving time for self and other family members, managing personal health, leisure activities, social gatherings with family members, relatives and friends, and outdoor engagements such as shopping, dining out, hospital appointments, etc. The consequences of caregiving for an individual with dysphagia also result in insufficient money to meet family needs and/or losing jobs, savings/ assets due to their primal consideration in fulfilling their partner's needs and necessities (Byeon, 2019; Coutts & Sayed, 2023; Coutts & Solomon, 2020; Hassib & Ostia, 2021). These caregiver issues were consistent in the current study as well. A general caregiver burden is experienced henceforth by most of the informal primary caregivers, which is closely associated with dysphagia and its related burdens.

5.3 Reliability of the Trans-Adapted CARES Tool

The reliability testing revealed good internal consistency and reliability of the translated CARES tool with a Cronbach's alpha between 0.9 and 1.00 for both subscales. The test-retest reliability measurement was performed, and the correlation coefficient was found to be 1.00, 0.986, and 1.00 for subscale 1 (Part A), subscale 2 (Part B), and total scores (total scale), respectively. The Cronbach's alpha values were found to be 1.000, 0.998, and 0.999 for Part A, Part B and the total scale of the translated tool. For the original CARES tool, internal consistency was evident for Part B, with a Cronbach's alpha of 0.77, unlike Part A, which had a Cronbach's alpha value of 0.65 (less than 0.7). However, the total scale had a Cronbach's alpha of 0.79, indicating significant internal consistency of the CARES tool. The internal reliability of another similar instrument, the Feeding/Swallowing Impact Survey (FS-IS; Lefton-Grief et al., 2014), which identifies and measures the stresses and issues of the caregivers of children with swallowing/feeding difficulties, was identified as very good. The Cronbach's alpha for this instrument was determined to be above 0.7 for all three subscales (daily activities, worries and feeding issues) and the total scale, which were 0.88, 0.85, 0.85 and 0.89, respectively. Considering these existing tools, which specifically identify and measure the dysphagia-related caregiver burdens and stresses, the currently trans-adapted tool exhibits higher Cronbach's alpha value and thus greater reliability and internal consistency.

5.4 Influence of Variables on Dysphagia-Related Burden

In the current study, the variables contributing to the caregivers' burden were identified as the duration of caregiving services, care recipient feeding status and care recipient dependency status. Other caregiver variables, such as age, gender, relationship status, and socioeconomic status, and care recipient variables, such as dysphagia etiology and duration of tube feeding, were found to have no significant association with dysphagia-specific caregiver burden. The discussion pertaining to caregiver and care recipient-related variables is provided in the subsections below.

5.4.1 Dysphagia-Related Burden and Caregiver-Related Variables

Caregiver variables, such as age, gender, and socioeconomic status of the caregiver, along with their relationship to the care recipient, were found to have no significant association with the dysphagia-related caregiver burden in the current study. The dysphagia-related burden experienced by the caregiver was also found to be almost consistent, irrespective of the underlying etiology of the swallowing impairment. These findings are congruent with the outcomes of the systematic review by Rangira et al. (2021). They discovered that the transformation in mealtime activities, meal preparations, responsibilities, lifestyle and routine, psychosocial disturbances, and dysphagia consequences like aspiration increased the caregiver's experienced burden irrespective of their age, gender, relationship with the care recipient and etiology of dysphagia.

The current study results do not yield a significant correlation between the age of the caregiver and the dysphagia-related caregiver burden. There are several other studies, however, not specific to caregivers of individuals with dysphagia, which yielded different findings (Chiari et al., 2021; Hergert & Cimino, 2021; Pagnini et al., 2010; Tramonti et al., 2015; Unsar et al., 2021; Williams et al., 2009). Unlike the current study, Chiari et al. (2021), Hergert and Cimino (2021), and Williams et al. (2009), in their study on neurological conditions, identified more burden to be experienced by younger adult caregivers compared to older caregivers. The responsibility of providing care provisions for the neurodegenerative disease population at an early age may impact their other aspects of life like higher education, financial strain, career and career opportunities, social activities and interactions, focusing on and caring for their personal life, children and/or other elderly family members. The study done by Unsar et al. (2021) on informal caregivers of cancer patients supports these findings since it also reports a greater burden, depression and anxiety levels among younger caregivers than older ones. However, another scenario where older caregivers caring for individuals with Amyotrophic Lateral Sclerosis experience more stress and burden in the case of prolonged care services has been reported in the studies of Pagnini et al. (2010) and Tramonti et al. (2015).

In the current study, even though women reported more behavioral and functional changes, emotional distress, physical burden, and social withdrawal and isolation when compared to men, it was not statistically significant. There are several studies, unlike dysphagia-specific caregiver burden studies, that support women caregivers to suffer a greater caregiver burden than men in terms of physical burden, emotional distress (depression, feeling abandoned, worry, etc.), social burden, and developmental burden such as feeling missing out on life's opportunities (Chiari et al., 2021; Given et al., 2004; Hergert & Cimino, 2021; Tramonti et al., 2015; Young & Kahana, 1989). However, the finding quoted by Arun et al. (2018) when the association between spousal caregiver burden and caregiver age and gender was assessed revealed no significant correlation between caregiver age and gender with the caregiver burden experienced, even though female spouses reported facing slightly more stress than male spousal caregivers of individuals with Schizophrenia. Despite not being performed on dysphagia-related caregiver burden, this study yielded a similar result to the present study findings.

The current study results revealed that the spouses experienced a slightly greater burden when compared to children, mother, daughter-in-law, or sister caregivers, albeit no statistically significant difference was identified across the groups. The findings of the current study indicated that irrespective of the relationship with the care recipient, the caregivers were bound to experience behavioral and functional changes and stresses during their caregiving services. When the relationship between the caregiver and the care recipient is considered, the other research findings are divergent, with several studies, nonspecific to dysphagia-related caregiver burden, stating that spouses, especially wives, bear a greater burden than others (Chiari et al., 2021; Tramonti et al., 2015), while some contradict these findings (Given et al., 2004; Hergert & Cimino, 2021; Tabloski et al.,2021; Young & Kahana, 1989). Children, children-in-law, and siblings were reported to have a higher burden than others in several studies, which was not specific to dysphagia (Given et al., 2004; Hergert & Cimino, 2021; Tabloski et al.,2021; Young & Kahana, 1989).

Beach et al. (2019), from their investigation concerning the effect of socioeconomic status on caregiver burden, identified poorer socioeconomic status not to be a reason for poor carer outcomes. Their findings correlated well with the current study results on the dysphagia population. Even though the upper-lower socioeconomic status group was found to experience a slightly greater burden, it was found to be statistically insignificant. No significant difference was found in dysphagia-specific caregiver burden between the upper-lower and middle-class caregivers in the current study. However, these findings cannot be generalised as completely acceptable due to the lack of participants from extreme socioeconomic statuses (lower and upper). Nevertheless, there are reports of lower socioeconomic group caregivers experiencing more burden than caregivers with middle and upper SES (Arun et al., 2018; Nikbakht et al., 2022), contradicting the findings of Kumari et al. (2018) who reported caregivers with higher SES to experience more burden.

The contradicting findings with respect to the caregiver variables, such as age, gender, relationship status, and socioeconomic status, in the caregiver burden studies in the dysphagia population and other conditions reflect the lack of adequate knowledge, exposure, and guidance in caregivers regarding dysphagia management at home along with the possible methodological variabilities across studies. This may be the reason for no significant difference in the dysphagia-related burden experienced by the caregivers irrespective of their age, gender, relationship status and socioeconomic status.

The current study's findings revealed a statistically significant negative correlation between caregiving duration and dysphagia-related caregiver-experienced burden, wherein a decrease in caregiver burden was observed as the duration of caregiving increased. Several studies, nonspecific to dysphagia-related caregiver burden studies, report a similar finding, especially in the elderly care recipient population, where a decrease in the experienced caregiver burden was reported with a longer duration of caregiving, while more burden was experienced with a shorter duration of caregiving (Graf et al., 2017; Johnson, 1998; Miller & Lawton, 1997; Phetsitong et al., 2019; Zainuddin et al., 2003). These findings may be due to the "adaptation effect" or "adaptive mechanism", which implies that the carers of elderly individuals understand, get accustomed and procure enhanced coping abilities to their care recipient's problem over time. In the current study, the caregivers perceived less burden with respect to changes in their behavioral and functional aspects when the caregiving duration was prolonged. Hence, this finding can be attributed to the previously mentioned possibilities, along with the decrease in dysphagia severity over time that may contribute to the reduced perceived burden among informal caregivers. On the contrary, Unsar et al. (2021) reported a greater caregiver burden and increased depression and anxiety among informal caregivers of cancer patients without dysphagia with increased caregiving duration. Other studies also report an increased caregiver burden associated with a prolonged caregiving duration (Arsha, 2020; Pinar Boluktas, 2022), while some report no significant association between caregiving duration and caregiver stress (Li et al., 1999).

5.4.2 Dysphagia-Related Caregiver Burden and Care Recipient-Related Variables

In the current study, the care recipient's dependency and feeding status were found to significantly affect the dysphagia-related caregiver burden. If the care recipient is incapable of self-care, especially eating and drinking, or dependent on tube feeding, it is likely to increase the burden of the caregiver. The other variables, namely, the etiology of dysphagia and duration of tube feeding, were found to have no significant association with the dysphagia-related caregiver burden.

An association between dysphagia-related caregiver burden and different dysphagia etiologies was not identified from the current study results. Supporting evidence for this finding is evident in the systematic review by Rangira et al. (2021), which reported a negative impact and enhanced caregiver burden among the caregivers of adults with dysphagia, irrespective of the etiology of dysphagia. Several other studies also, which investigated the dysphagia-related caregiver burden in carers of individuals with dysphagia associated with varied etiologies never highlighted any difference in the perceived dysphagia-related caregiver burden with varying dysphagia etiologies (Coutts & Sayed, 2023; Hassib & Ostia, 2021; Hillege, 2006; Johansson & Johansson, 2009; Shune & Namasivayam-MacDonald, 2019a; 2019b). Similar are the findings in the present study, where no association was found between dysphagia-related caregiver burden and different dysphagia etiologies. This indicates that, regardless of the underlying pathology, dysphagia-related stresses and consequences are experienced by the caregivers without any significant variation. There are currently insufficient studies that looked into the differences in the experienced dysphagia-related caregiver burden with varying etiologies of dysphagia. This suggests a dire need for more in-depth research focusing on the matter.

The care recipients who relied on caregivers for their daily activities and self-care, including feeding, imposed a more significant burden and changes to the caregivers’ behavioral and functional aspects, as identified from the current study findings. This may be due to their expanded responsibilities and resultant time constraints and hindrance in performing their activities of daily living and other necessary and/or favoured activities that caused the perception of increased dysphagia-specific caregiver burden in the carers of individuals with dysphagia. Byeon (2019) stated that the burden experienced by the caregivers of individuals with dysphagia was also associated with the patient's extreme dependency on them. Studies on other pathological or chronic illness conditions also reflect a similar finding where the caregivers are reported to experience more burden with the care recipient's reduced self-care capability or increased dependency levels (Garre-Olmo et al., 2016; Isac et al., 2021; Jafari et al., 2018; Phetsitong et al., 2019; Rodríguez-González et al., 2021; Sabzwari et al., 2016).

The caregivers of care recipients dependent on tube feeding were found to experience a greater burden in terms of physical and functional changes and emotional burden than those involved in oral feeding in the present study. Previous studies have reported an increased burden, stress and anxiety in caregivers managing tube feedings as they feel inadequately proficient in managing the same, increasing the risk of tube feeding complications (Namasivayam-MacDonald & Shune,2018; Penner et al., 2012). A "heavy burden" was reported by the caregivers if the care recipient was tube-dependent for feeding (Bentur et al., 2015; Namasivayam-MacDonald & Shune, 2018). Other studies report an increase in the emotional stresses, responsibilities and time constraints if the care recipient is tube-fed, leading to a greater carer experienced dysphagia-related burden (Hassib & Ostia, 2021; Johansson & Johansson, 2009; Rangira et al., 2021). Coutts and Solomon (2020) also identified that caregivers experienced financial burden and fear concerning tube feeding-related activities when compared to oral feeding. Penner et al. (2012) discovered that the caregivers experienced increased physical and psychological burdens related to tube feeding as a consequence of the strict schedule that came with tube feeding in caregivers’ lives, which left them with a lack of leisure time, altered sleep patterns, and impaired mealtime activities and social life. These findings correlated with the results of the present study, which identified the caregivers of care recipients dependent on tube feeding to experience a greater burden than those involved in oral feeding. However, there are some differing findings from the current study’s results. A contradicting report was highlighted by Hiatt et al. (2021), where caregivers regarded the gastrostomy tube as a crucial aspect of treatment and a means to assist their partner's nutrient intake when food and liquid consumption became unmanageably problematic, instead of perceiving tube feeding-related activities as burdensome. Another study also reported that the care recipients dependent on food texture modification significantly increased the caregiver burden compared to those dependent on tube feeding (Suzuki et al., 2022), which again is not consistent with the results of the current study.

The correlation between the duration of tube feeding and the dysphagia-related caregiver burden was found to be statistically insignificant in the current study. This study obtained limited data on caregivers associated with tube feeding from less than one month to over 12 months. The study findings indicate that no significant difference was present in the caregivers’ experienced burden, even if he/she had been handling the tube feeding responsibilities for less than a month or about 12 months. These findings cannot be generalized due to the smaller sample size of the tube-feeding population in the present study and the lack of previous studies on the specified objective.

Chapter VI

Summary & Conclusion

The burden of care experienced by caregivers has been explored extensively in several different populations (e.g., stroke, neurodegenerative diseases, psychiatric disorders) till the present, and the tools to identify and measure the same are available and easily accessible worldwide. However, research on dysphagia-specific caregiver burden is limited but has gained more attention recently. The recent development of the CARES screening tool opened a way to understand and cater to the burdens and needs of caregivers of individuals with dysphagia. The increasing population of individuals with dysphagia and their caregivers in a multilingual country like India necessitates the need for a similar quick, user-friendly, and straightforward tool in the Indian context for the early identification of dysphagia-specific caregiver burden. 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 strengthen the trans-adaptation and validation of CARES in Indian context (Malayalam language).

Screening tools are opted as the primary evaluation methods as they are considered rapid, easy and simple to use, with good internal consistency. A lack of such a screening tool to evaluate the dysphagia-related caregiver burden in the Indian context encouraged the adaptation, translation, and validation of CARES to Malayalam.

The current study was undertaken to trans-adapt and validate the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES), a screening tool developed by Shune and Namasivayam-MacDonald (2020), which assesses the impact of dysphagia on a caregiver and the associated caregiver burden across a wider age group and across several etiologies that lead to dysphagia, to Malayalam.

The adaptation, translation and validation of the current screening tool was carried out in four phases. The translation process followed complied with the standard WHO guidelines for the translation and adaptation of tools. The final version of the adapted screening tool incorporated all the valid changes recommended throughout the translation and validation process before using it on 60 primary caregivers of individuals with dysphagia. The adapted Malayalam version-CARES is a checklist consisting of 26 statements divided into two parts, where Part A assesses the behavioral and functional changes encountered over the last month of their caregiving, and Part B evaluates the emotional burden faced by the adult caregivers as a consequence of their adult care recipient’s dysphagia over the last month. The tool will help the clinician identify the sources and areas of burden that a caregiver confronts during their journey of caregiving for an adult with dysphagia. The construct validity of the adapted tool was determined using the FOIS and the Malayalam version-CBAS questionnaire. Test-retest reliability was carried out on 10% of the total participants post 2 weeks of the initial data collection.

The translated tool proved to be statistically valid and reliable with a good internal consistency. A good association was found between the dysphagia-related caregiver burden assessed using the Malayalam version-CARES and the symptom severity of dysphagia, indirectly measured based on FOIS level and the general caregiver burden. The participant caregivers were found to suffer more dysphagia-specific burden with the care recipient’s increased symptom severity of dysphagia, feeding and self-care dependency, nonoral intake (tube feeding), and increased general burden. The dysphagia-specific burden was found to gradually reduce in the caregivers as the duration of care services increased. Other caregiver and care recipient-related variables such as caregiver age, caregiver gender, relationship status, socioeconomic status, dysphagia etiology, and duration of tube feeding were found to not contribute to dysphagia-related caregiver burden. However, further in-depth study 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 Study Implications

1. The adapted CARES tool provides healthcare professionals, especially therapists dealing with dysphagia, an idea and awareness of the dysphagia-related caregiver burden experienced by a caregiver.
2. The adapted CARES questionnaire in Malayalam can be used as a tool to assess and identify dysphagia-related caregiver burden in the Indian context by practising SLPs.
3. This validated tool can provide information about the sources and extent of dysphagia-related caregiver burden encountered by a caregiver.
4. The study could identify the most frequent and burdensome issues faced by caregivers during their caregiving venture in the Indian scenario.
5. The information obtained from the tool can guide the clinicians in deciding and forming the required healthcare specialist team (e.g., psychologist, social worker, family centered therapy, etc.) and support to cater to the needs and problems of the patients and their caregivers (e.g., providing more education regarding dysphagia, its consequences, and management strategies, facilitating improved training regarding the same, delivering constant and sufficient support and resources, etc.).
6. The possible early identification of the burden with this screening tool would help develop organized, effective and impactful tailor-made intervention strategies involving the entire family unit along with the patient and his/her

primary caregivers, which can promote the quality of life of caregivers and their care recipients, particularly in the Malayalam-speaking population.

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

6.2 Study limitations

The interaction effect analysis between the study variables could not be calculated due to sample size. Perry et al. (2022) reported dysphagia-related poorer quality of life of the caregiver associated with the care recipient’s combined impact of ageing and disease course. In the current study as well, there are high chances for the existence of an interaction effect, which might be contributing to the caregiver’s reported stresses and burdens. The limited sample size in the undertaken study does not facilitate the assessment of the interaction effect of variables on the caregiver-reported dysphagia-related burden. Several potential variables like family type, family size, duration of dysphagia, occupation of the caregiver, presence of multiple caregivers and /or care recipients, cognitive status of the care recipient, and the type of tube feed used were not considered, which might contribute to the caregiver burden. The study lacks all the possible causes of dysphagia, relationship statuses, and socioeconomic status groups, as well as the limited number of participants under certain variables, which could affect the generalization of the results. The translated tool could not be validated in the pediatric population. The sensitivity and specificity of the adapted tool could not be established.

6.3 Future Directions

1. The present study could be carried out in-depth, including all the potential variables contributing to the dysphagia-specific caregiver burden experienced by the caregiver.

2. The sample size could be expanded and made diverse with adequate participants under each undertaken variable.
3. The interaction effect between variables could be calculated.
4. The screening tool could be translated and adapted to other languages for use with various Indian languages.
5. A cut-off score could be established and categorize the burden into different severity levels.
6. Sensitivity and specificity of the translated tool could be established.
7. The tool could be validated in the pediatric population who have dysphagia.

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APPENDIX A

All India Institute of Speech and Hearing, Naimisham Campus, Manasagangothri, Mysore-570006

CONSENT FORM

സമ്മത പത്രം

പങ്കെടുക്കുന്നയാൾക്ക്/പരിചരിക്കുന്നയാൾക്കുള്ള വിവരങ്ങൾ

എന്റെ പ്രബന്ധ പരിപാടിയുടെ ഭാഗമായി 2nd MSc SLP-യിൽ പഠിക്കുന്ന Ms Namreda S Arakkal, "ട്രാൻസ്-അഡാപ്റ്റേഷൻ ആൻഡ് വാലിഡേഷൻ ഓഫ് കാർഗിവർ അനാലിസിസ് ഓഫ് റിപോർട്ടഡ് എക്സ്പീരിയൻസസ് വിത്ത് സ്വല്ലോവിങ് ഡിസോർഡേഴ്സ് (CARES)" എന്ന തലക്കെട്ടിൽ Dr Swapna N-നിന്റെ (സ്പീച്ച് പാത്തോളജി പ്രൊഫസറും, കോർഡിനേറ്റർ-സെന്ററർ ഫോർ സ്വാലോവിംഗ് ഡിസോർഡേഴ്സ്, AIISH, മൈസൂരു) മാർഗ്ഗനിർദ്ദേശത്തിൽ ഒരു പഠനം നടത്തുന്നു. ഡിസ്ഫാജിയ ബാധിച്ച വ്യക്തികളെ പരിചരിക്കുന്നവർ അനുഭവിക്കുന്ന പ്രശ്നങ്ങൾ മനസിലാക്കുന്നതിനും അതിനനുസരിച്ച് അവരുടെ ഭാരം കുറയ്ക്കുന്നതിനും അവരുടെ ജീവിതനിലവാരം മെച്ചപ്പെടുത്തുന്നതിനും എന്നുള്ള ലക്ഷ്യത്തോടെയാണ് ഈ പഠനം ഏറ്റെടുത്തിരിക്കുന്നത്. CARES ചോദ്യാവലിയുടെ ഇംഗ്ലീഷ് പതിപ്പ് മലയാളത്തിലേക്ക് പൊരുത്തപ്പെടുത്തുകയും വിവർത്തനം ചെയ്യുകയും സാധൂകരിക്കുകയും ചെയ്യുന്നതാണ് പഠനം. ഈ നടപടിക്രമം കേടുപാടുകൾ വരുത്താത്തതും ഗവേഷണ ആനുകൂല്യങ്ങൾ മാത്രമുള്ളതുമാണ്, പങ്കെടുക്കുന്നവർക്ക് അതിൽ നിന്ന് സാമ്പത്തിക നേട്ടങ്ങളൊന്നും ലഭിക്കുന്നതല്ല. പങ്കെടുക്കുന്നവർ 2 ചോദ്യാവലി പൂരിപ്പിക്കേണ്ടതുണ്ട്, അത് ഡിസ്ഫാഗിയയ്ക്ക് പ്രത്യേകമായുള്ള പരിചരണഭാരവും പൊതുവായ പരിചരണഭാരവും വിലയിരുത്തുന്നു, അവ രണ്ടും മലയാളത്തിലായിരിക്കും. പരിചരണം സ്വീകരിക്കുന്നയാളുടെ ഭക്ഷണം കഴിക്കുന്ന രീതിയും നിലവാരവും അന്വേഷകൻ വിലയിരുത്തുന്നതായിരിക്കും. വിവർത്തനം ചെയ്ത ചോദ്യാവലി ക്ലിനിക്കൽ ആവശ്യങ്ങൾക്കായി ഉപയോഗിക്കുന്നതായിരിക്കും. നിങ്ങളുടെ ഐഡന്റിറ്റിയും ഈ ഡാറ്റയും രഹസ്യമായി സൂക്ഷിക്കും എന്ന ഉറപ്പോടെ നിലവിലെ പഠനത്തിൽ പങ്കെടുക്കാൻ ഞാൻ നിങ്ങളോട് അഭ്യർത്ഥിക്കുന്നു. അന്വേഷകനോ അന്വേഷണ സ്ഥാപനത്തിനോ നിങ്ങളുടെ പങ്കാളിത്തത്തിൽ യാതൊരു തരത്തിലുള്ള സ്വാധീനമോ സമ്മർദ്ദമോ ഇല്ല. ഡിസ്ഫാഗിയ ബാധിച്ച വ്യക്തികളെ പരിചരിക്കുന്നവർ അഭിമുഖീകരിക്കുന്ന ഭാരവും സമ്മർദ്ദവും മനസിലാക്കുന്നതിനും ഈ പ്രശ്നങ്ങൾ സംയോജിപ്പിച്ച് ഫലപ്രദമായ ഇടപെടൽ ആസൂത്രണം ചെയ്യുന്നതിനും, പരിചരണം നൽകുന്നവരുടെയും അവരുടെ പരിചരണം സ്വീകരിക്കുന്നവരുടെയും ജീവിതനിലവാരം മെച്ചപ്പെടുത്തുന്നതിനും പഠനത്തിലെ നിങ്ങളുടെ ദയയുള്ള സഹകരണം വളരെയധികം സഹായിക്കും.

പങ്കാളിത്തത്തിനുള്ള സമ്മതം

പഠനത്തിന്റെ ലക്ഷ്യങ്ങൾ, നടപടിക്രമങ്ങൾ എന്നിവയെക്കുറിച്ച് എന്നെ അറിയിച്ചിട്ടുണ്ട്. പഠനത്തിൽ എന്റെ പങ്കാളിത്തത്തിന്റെ സാധ്യമായ അപകട- ആനുകൂല്യങ്ങൾ എനിക്ക് വ്യക്തമായി മനസ്സിലായിട്ടുണ്ട്. പഠനത്തെക്കുറിച്ചുള്ള ചോദ്യങ്ങൾ ചോദിക്കാനും എനിക്ക് അവസരം നൽകിയിട്ടുണ്ട്. പഠനത്തിൽ പങ്കെടുക്കുന്നതിൽ ഞാൻ, ഡിസ്ഫാഗിയ ബാധിച്ച വ്യക്തികളുടെ പ്രാഥമിക പരിചാരകൻ എന്ന നിലയിൽ, എന്റെ പ്രശ്നങ്ങളും ഭാരങ്ങളും പരാമർശിക്കുന്ന ചോദ്യാവലി പൂരിപ്പിക്കുന്നതിന് സമ്മതം നൽകുന്നു. ഈ പഠനത്തിൽ നിന്ന് എപ്പോൾ വേണമെങ്കിലും എന്റെ പങ്കാളിത്തം നിരസിക്കാനോ സമ്മതം പിൻവലിക്കാനോ എനിക്ക് അവകാശമുണ്ടെന്ന് ഞാൻ മനസ്സിലാക്കുന്നു. ഈ പഠനത്തിന് എന്നെത്തന്നെ വിധേയമാക്കുന്നതിലൂടെ, അന്വേഷകൻ നടത്തുന്ന വിലയിരുത്തലുകൾക്ക് കൂടുതൽ സമയം നൽകേണ്ടിവരുമെന്നും എനിക്കറിയാം. എന്നോട് പരാമർശിച്ചിട്ടുള്ള അവകാശങ്ങളുടെയോ വ്യവസ്ഥകളുടെയോ ലംഘനം ഉണ്ടായാൽ AIISH എത്തിക്കൽ കമ്മിറ്റി ചെയർമാനോട് എഴുതാൻ എനിക്ക് സ്വാതന്ത്ര്യമുണ്ട്. പഠനത്തിൽ ചേരുന്നതിനുള്ള എന്റെ പൂർണ്ണ സമ്മതം ഞാൻ ഇതിനാൽ നൽകുന്നു.

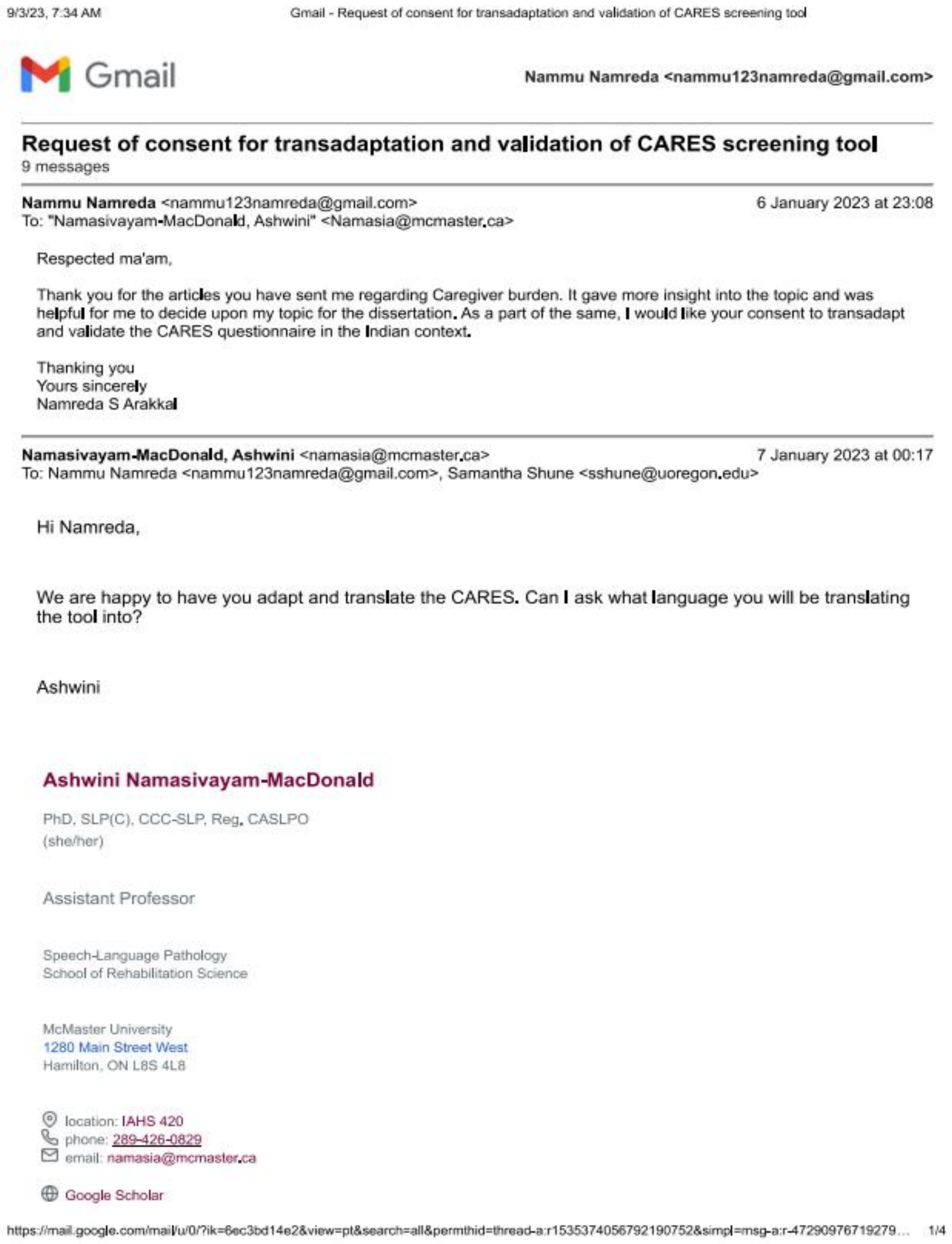
ഞാൻ, ________________________________, ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ എന്റെ സമ്മതം നൽകുന്നു

പങ്കെടുക്കുന്നയാളുടെ/പരിചരിക്കുന്നയാളുടെ ഒപ്പ്　　അന്വേഷകന്റെ ഒപ്പ്

പേര്, വിലാസം, ഫോൺ നമ്പർ:　　തീയതി:

APPENDIX B

CONSENT FROM AUTHOR



9/3/23, 7:34 AM Gmail - Request of consent for transadaptation and validation of CARES screening tool

Gmail **Nammu Namreda <nammu123namreda@gmail.com>**

Request of consent for transadaptation and validation of CARES screening tool

9 messages

Nammu Namreda <nammu123namreda@gmail.com> 6 January 2023 at 23:08
To: "Namasivayam-MacDonald, Ashwini" <Namasia@mcmaster.ca>

Respected ma'am,

Thank you for the articles you have sent me regarding Caregiver burden. It gave more insight into the topic and was helpful for me to decide upon my topic for the dissertation. As a part of the same, I would like your consent to transadapt and validate the CARES questionnaire in the Indian context.

Thanking you
Yours sincerely
Namreda S Arakkal

Namasivayam-MacDonald, Ashwini <namasia@mcmaster.ca> 7 January 2023 at 00:17
To: Nammu Namreda <nammu123namreda@gmail.com>, Samantha Shune <sshune@uoregon.edu>

Hi Namreda,

We are happy to have you adapt and translate the CARES. Can I ask what language you will be translating the tool into?

Ashwini

Ashwini Namasivayam-MacDonald

PhD, SLP(C), CCC-SLP, Reg. CASLPO
(she/her)

Assistant Professor

Speech-Language Pathology
School of Rehabilitation Science

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location: IAHS 420
phone: 289-426-0829
email: namasia@mcmaster.ca

Google Scholar

https://mail.google.com/mail/u/0/?ik=6ec3bd14e2&view=pt&search=all&permthid=thread-a:r1535374056792190752&simpl=msg-a:r-47290976719279… 1/4

APPENDIX C

MALAYALAM VERSION-CARES

The final version of “Malayalam version of the CARES”

ഭാഗം എ: പെരുമാറ്റപരവും പ്രവർത്തനപരവുമായ മാറ്റങ്ങളുടെ പട്ടിക

/bʱaːgam e:/ /peɾumaːt̠t̠apaɾaʋum praʋart̪t̪anapaɾaʋumaːja maːt̠t̠aŋŋaɭuʈe paʈʈika/

താഴെപ്പറയുന്ന ഓരോ പ്രസ്താവനകൾക്കും, കഴിഞ്ഞ മാസത്തെ നിങ്ങളുടെ പ്രിയപ്പെട്ടയാളുടെ /പരിചരണ സ്വീകർത്താവിന്റെ ഭക്ഷണം അല്ലെങ്കിൽ വിഴുങ്ങൽ ബുദ്ധിമുട്ടുകളെ കുറിച്ച് പ്രത്യേകം ചിന്തിക്കുക. പ്രസ്താവനയിൽ വിവരിച്ചിരിക്കുന്ന സാഹചര്യം നിങ്ങളെ അലോസരപ്പെടുത്തിയിട്ടുണ്ടോ? അത് സംഭവിച്ചിട്ടില്ലെങ്കിൽ, ദയവായി “N/A” സൂചിപ്പിക്കുക.

/t̪aːɻepparajun̪n̪a oːɾoː prast̪aːʋanakaɭkkum kaɻiɲɲa maːsat̪t̪e n̪iŋŋaɭuʈe prijappeʈʈajaːɭuʈe/paɾit͡ʃaɾaɳa sʋiːkart̪t̪aːʋint̠e bʱakʂaɳam alleŋkil ʋiɻuŋŋal bud̪d̪ʱimuʈʈukaɭe kurit͡ʃt͡ʃə prat̪jeːkam t͡ʃin̪t̪ikkuka/. /prast̪aːʋanajil ʋiʋaɾit͡ʃt͡ʃiɾikkun̪n̪a saːɦat͡ʃaɾjam n̪iŋŋaɭe aloːsaɾappeʈut̪t̪ijiʈʈuɳʈoː/? /at̪ə sambʱaʋit͡ʃt͡ʃiʈʈilleŋkil, d̪ajaʋaːji “N/A” suːt͡ʃippikkuka/.

	കഴിഞ്ഞ മാസത്തിൽ, ഈ സാഹചര്യം നിങ്ങളെ അലട്ടിയിട്ടുണ്ടോ? /kaɻiɲɲa maːsat̪t̪il iː saːɦat͡ʃaɾjam n̪iŋŋaɭe alaʈʈijiʈʈuɳʈoː/?		
1. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, അവർക്ക് ഭക്ഷണം തയ്യാറാക്കുവാനും കഴി പ്പിക്കുവാനും (അഥവാ അവർ കഴിക്കുവാനും) അധിക സമയം ആവശ്യം ആകാറുണ്ട് (ഉദാ, അനുയോജ്യമായ ഭക്ഷണങ്ങൾ കണ്ടെത്തുന്നതിന്, ഭക്ഷണം പാകം ചെയ്യുന്നതിന്, ട്യൂബ് ഫീഡിംഗിന്, പ്രിയപ്പെട്ട ആൾ തിന്നുന്നതും/കുടിക്കുന്നതും നിരീക്ഷിക്കുന്നതിന്). /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam aʋarkkə bʱakʂaɳam t̪ajjaːraːkkuʋaːnum kaɻippikkuʋaːnum (at̪ʰaʋaː aʋar	അതെ /at̪e/	ഇല്ല /illa/	N/A

	kaɻikkuʋaːnum) ad̪ʱika samajam aːʋaʃjamaːkaːruɳʈə/ (/ud̪aː, anujoːɟjamaːja bʱakʂaɳaŋŋaɭ kaɳʈet̪t̪un̪n̪at̪inə, bʱakʂaɳam paːkam t͡ʃejjun̪n̪at̪inə, ʈjuːbə fiːɖiginə, prijappeʈʈa aːɭ t̪in̪n̪un̪n̪at̪um kuʈikkun̪n̪at̪um n̪iɾiːkʂikkun̪n̪at̪inə/).			
2.	എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, ഭക്ഷണ സമയവും പോഷകാഹാരവുമായി ബന്ധപ്പെട്ട എന്റെ ഉത്തരവാദിത്തങ്ങൾ വർദ്ധിച്ചതായി തോന്നാറുണ്ട് (ഉദാ. കടയിൽ നിന്ന് സാധനങ്ങൾ വാങ്ങിക്കുന്നത്, പാചകം ചെയ്യുന്നത്, ട്യൂബ് ഫീഡിംഗ് ബന്ധപ്പെട്ടുള്ള കാര്യങ്ങൾ എന്നിവ). /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam, bʱakʂaɳa samajaʋum poːʂakaːɦaːɾaʋumaːji ban̪d̪ʱappeʈʈa ent̠e ut̪t̪aɾaʋaːd̪it̪t̪aŋŋaɭ ʋard̪d̪ʱit͡ʃt͡ʃat̪aːji t̪oːn̪n̪aːruɳʈə/ (/ud̪aː kaʈajil n̪in̪n̪ə saːd̪ʱanaŋŋaɭ ʋaːŋŋikkun̪n̪at̪ə, paːt͡ʃakam t͡ʃejjun̪n̪at̪ə, ʈjuːbə fiːɖigə ban̪d̪ʱappeʈʈuɭɭa kaːɾjaŋŋaɭ, en̪n̪iʋa/).	അതെ /at̪e/	ഇല്ല /illa/	N/A
3.	എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം അവരുടെ പോഷകാഹാര ആവശ്യങ്ങളുമായി ബന്ധപ്പെട്ട ചെലവുകൾ വർദ്ധിച്ചിരിക്കുന്നു (ഉദാ. ട്യൂബ് ഫീഡിംഗിനുള്ള സാധനങ്ങൾ, ഭക്ഷണം കട്ടിയാക്കുന്നതിനുള്ള ഉൽപ്പന്നങ്ങൾ അല്ലെങ്കിൽ കട്ടിയുള്ള ദ്രാവകങ്ങൾ, അനുയോജ്യമായ ഭക്ഷണങ്ങളും മറ്റും വാങ്ങുന്നതിനുള്ള ചിലവുകൾ). /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam aʋaɾuʈe poːʂakaːɦaːɾa aːʋaʃjaŋŋaɭumaːji ban̪d̪ʱappeʈʈa t͡ʃelaʋukaɭ ʋard̪d̪ʱit͡ʃt͡ʃiɾikkun̪n̪u/ (/ud̪aː, ʈjuːbə fiːɖiginuɭɭa saːd̪ʱanaŋŋaɭ, bʱakʂaɳam kaʈʈijaːkkun̪n̪at̪inuɭɭa ulppan̪n̪aŋŋaɭ alleŋkil kaʈʈijuɭɭa d̪ɾaːʋakaŋŋaɭ,	അതെ /at̪e/	ഇല്ല /illa/	N/A

anujoːɟjamaːja bʱakʂaɳaŋŋaɭum mat̠t̠um ʋaːŋŋun̪n̪at̪inuɭɭa t͡ʃilaʋukaɭ/).			
4. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ ഞാൻ കൈകാര്യം ചെയ്യുന്ന രീതിയോട് മറ്റ് കുടുംബാംഗങ്ങൾ എന്നോട് യോജിക്കാറില്ല. /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ ɲaːn kai̯kaːɾjam t͡ʃejjun̪n̪a ɾiːt̪ijoːʈə mat̠t̠ə kuʈumbaːmgaŋŋaɭ en̪n̪oːʈə joːɟikkaːrilla/.	അതെ /at̪e/	ഇല്ല /illa/	N/A
5. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കൈകാര്യം ചെയ്യുന്നത് എന്റെ ദിനചര്യയെ തടസ്സപ്പെടുത്താറുണ്ട്. (ഉദാ, ജോലി, സ്കൂൾ ജോലി, വീട്ടുജോലികൾ) /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kai̯kaːɾjam t͡ʃejjun̪n̪at̪ə ent̠e d̪inat͡ʃaɾjaje t̪aʈassappeʈut̪t̪aːruɳʈə/ (/ud̪aː, ɟoːli, skuːɭ ɟoːli, ʋiːʈʈuɟoːlikaɭ/).	അതെ /at̪e/	ഇല്ല /illa/	N/A
6. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കൈകാര്യം ചെയ്യുന്നതിനാൽ ഞാൻ ചെയ്യാൻ ആഗ്രഹിക്കുന്ന മറ്റ് കാര്യങ്ങളിൽ നിന്ന് ഒഴിഞ്ഞു നിക്കേണ്ടതായി തോന്നാറുണ്ട്. (ഉദാ. ഒഴിവുസമയ പ്രവർത്തനങ്ങൾ). /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kai̯kaːɾjam t͡ʃejjun̪n̪at̪inaːl ɲaːn t͡ʃejjaːn aːgraɦikkun̪n̪a mat̠t̠ə kaːɾjaŋŋaɭil n̪in̪n̪ə oɻiɲɲu n̪ikkeːɳʈat̪aːji t̪oːn̪n̪aːruɳʈə/ (/ud̪aː, oɻiʋu samaja praʋart̪t̪anaŋŋaɭ/).	അതെ /at̪e/	ഇല്ല /illa/	N/A
7. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ട് കാരണം, ഞാനും ആ വ്യക്തിയും ഒരുമിച്ച് ഭക്ഷണം കഴിക്കുന്ന അവസരങ്ങൾ മുമ്പത്തേക്കാൾ കുറഞ്ഞു. /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈəkaːɾaɳam ɲaːnum aː ʋjakt̪ijum oɾumit͡ʃt͡ʃə bʱakʂaɳam kaɻikkun̪n̪a aʋasaɾaŋŋaɭ mumpat̪t̪eːkkaːɭ kuraɲɲu/.	അതെ /at̪e/	ഇല്ല /illa/	N/A

8. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, ഞാൻ ആഗ്രഹിക്കുന്നത്ര തവണ മറ്റുള്ളവരുമായി പദ്ധതികൾ ആസൂത്രണം ചെയ്യാറില്ല (ഉദാ. ട്രിപ്പ് പോകുന്നത്, ഷോപ്പിംഗ് പോകുന്നത്, കുടുംബ സംഗമം എന്നിവ). /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam ɲaːn aːgɾaɦikkun̪n̪at̪ra t̪aʋaɳa mat̠t̠uɭɭaʋaɾumaːji pad̪d̪ʱat̪ikaɭ aːsuːt̪ranam t͡ʃejjaːrilla/ (/ud̪aː, ʈrippə poːkun̪n̪at̪ə, ʂoːppimgə poːkun̪n̪at̪ə, kuʈumba samgamam en̪n̪iʋa/)	അതെ /at̪e/	ഇല്ല /illa/	N/A
9. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ട് കാരണം, എനിക്ക് ഇഷ്ടമുള്ളത്രയും തവണ ഞങ്ങൾക്ക് പുറത്ത് പോയി കഴിക്കാൻ പറ്റാറില്ല. /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈə kaːɾaɳam enikkə iʂʈamuɭɭat̪rajum t̪aʋaɳa ɲaŋŋaɭkkə purat̪t̪ə poːji kaɻikkaːn pat̠t̠aːrilla/.	അതെ /at̪e/	ഇല്ല /illa/	N/A
10. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ട് കാരണം, അവർക്ക് കഴിക്കാൻ പറ്റാത്ത ഭക്ഷണ പദാർത്ഥങ്ങളും/പാനീയങ്ങളും ഞാൻ കഴിക്കുന്നത് ഒഴിവാക്കാറുണ്ട്. /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈə kaːɾaɳam aʋarkkə kaɻikkaːn pat̠t̠aːt̪t̪a bʱakʂaɳa pad̪aːrt̪t̪ʰaŋŋaɭum paːniːjaŋŋaɭum ɲaːn kaɻikkun̪n̪at̪ə oɻiʋaːkkaːruɳʈə/.	അതെ /at̪e/	ഇല്ല /illa/	N/A

മുകളിലുള്ള 10 പ്രസ്താവനകളിൽ, ഏതാണ് നിങ്ങളെ ഏറ്റവും അലട്ടുന്നത്? നമ്പർ

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/mukaɭiluɭɭa 10 prast̪aːʋanakaɭil, eːt̪aːɳə n̪iŋŋaɭe eːt̠t̠aʋum alaʈʈun̪n̪at̪ə/? /n̪ampar/

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ഭാഗം ബി: പരിചാരകൻ അനുഭവിക്കുന്ന സമ്മർദ്ദങ്ങൾ സൂചിപ്പിക്കുന്ന പട്ടിക

/bʱaːgam bi:/ /paɾit͡ʃaːɾakan anubʱaʋikkun̪n̪a sammard̪d̪aŋŋaɭ suːt͡ʃippikkun̪n̪a paʈʈika/

താഴെപ്പറയുന്ന ഓരോ പ്രസ്താവനകൾക്കും, കഴിഞ്ഞ മാസത്തെ നിങ്ങളുടെ പ്രിയപ്പെട്ടയാളുടെ/പരിചരണ സ്വീകർത്താവിന്റെ ഭക്ഷണം അല്ലെങ്കിൽ വിഴുങ്ങൽ ബുദ്ധിമുട്ടുകളെ കുറിച്ച് പ്രത്യേകം ചിന്തിക്കുക. പ്രസ്താവന നിങ്ങൾക്ക് ശരിയാണോ?

/t̪aːɻepparajun̪n̪a oːɾoː prast̪aːʋanakaɭkkum, kaɻiɲɲa maːsat̪t̪e n̪iŋŋaɭuʈe prijappeʈʈajaːɭuʈe/paɾit͡ʃaɾaɳa sʋiːkart̪t̪aːʋint̠e bʱakʂaɳam alleŋkil ʋiɻuŋŋal bud̪d̪ʱimuʈʈukaɭe kuɾit͡ʃt͡ʃə prat̪jeːkam t͡ʃin̪t̪ikkuka/. /prast̪aːʋana n̪iŋŋaɭkkə ʃaɾijaːɳoː/?

	കഴിഞ്ഞ മാസത്തിൽ താഴെ പറഞ്ഞിട്ടുള്ള പ്രസ്താവന നിങ്ങൾക്ക് ശരിയായിട്ടുണ്ടോ? /kaɻiɲɲa maːsat̪t̪il t̪aːɻe paɾaɲɲiʈʈuɭɭa prast̪aːʋana n̪iŋŋaɭkkə ʃaɾijaːjiʈʈuɳʈoː/?	
1. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കൈകാര്യം ചെയ്യാൻ ഞാൻ തയ്യാറല്ലെന്ന് എനിക്ക് തോന്നാറുണ്ട് (ഉദാ. ട്യൂബ് ഫീഡിംഗ്, ദ്രാവകങ്ങൾ കട്ടിയാക്കുന്നത്, ഭക്ഷണം കഴിക്കുമ്പോൾ ശ്വാസം കിട്ടാതെ വരുന്ന സന്ദർഭങ്ങൾ). /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kai̯kaːɾjam t͡ʃejjaːn ɲaːn t̪ajjaːrallen̪n̪ə enikkə t̪oːn̪n̪aːruɳʈə/ (/ud̪aː., ʈjuːbə fiːɖigə, d̪ɾaːʋakaŋŋaɭ kaʈʈijaːkkun̪n̪at̪ə, bʱakʂaɳam kaɻikkumpoːɭ ʃʋaːsamkiʈʈaːt̪e ʋaɾun̪n̪a san̪d̪arbʱaŋŋaɭ/).	അതെ /at̪e/	ഇല്ല /illa/
2. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, അവർക്ക് വേണ്ടത്ര പോഷകാഹാരം ലഭിക്കുന്നുണ്ടെന്ന് ഉറപ്പു വരുത്താൻ പ്രയാസമായി എനിക്ക് തോന്നാറുണ്ട്. /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam aʋarkkə ʋeːɳʈat̪ra	അതെ /at̪e/	ഇല്ല /illa/

poːʂakaːɦaːɾam labʱikkun̪n̪uɳʈen̪n̪ə urappu ʋaɾut̪t̪aːn prajaːsamaːji enikkə t̪oːn̪n̪aːruɳʈə/.		
3. എന്റെ പ്രിയപ്പെട്ടയാൾ അവരുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ പരിഹരിക്കുന്നതിനായി അവർക്ക് കഴിയുന്നത്രയും ശ്രമിക്കുന്നില്ല എന്ന് എനിക്ക് തോന്നാറുണ്ട്. /ent̠e prijappeʈʈajaːɭ aʋaɾuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ paɾiɦaɾikkun̪n̪at̪inaːji aʋarkkə kaɻijun̪n̪at̪rajum ʃramikkun̪n̪illa en̪n̪ə enikkə t̪oːn̪n̪aːruɳʈə/.	അതെ /at̪e/	ഇല്ല /illa/
4. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ട് കാരണം, അവർക്ക് ഏത് നിമിഷവും ഭക്ഷണം കഴിക്കുമ്പോൾ ശ്വാസനാളത്തിലേക്ക് അത് കടന്ന് ശ്വാസം കിട്ടാത്ത അവസ്ഥ വരുമെന്ന് ഞാൻ ഭയപ്പെടാറുണ്ട്. /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈə kaːɾaɳam aʋarkkə eːt̪ə n̪imiʂaʋum bʱakʂaɳam kaɻikkumpoːɭ ʃʋaːsanaːɭat̪t̪ileːkkə at̪ə kaʈan̪n̪ə ʃʋaːsam kiʈʈaːt̪t̪a aʋast̪ʰa ʋaɾumen̪n̪ə ɲaːn bʱajappeʈaːruɳʈə/.	അതെ /at̪e/	ഇല്ല /illa/
5. എന്റെ പ്രിയപ്പെട്ടയാൾക്ക് കഴിക്കാൻ കഴിയാത്ത ഭക്ഷണ പദാർത്ഥങ്ങളും/പാനീയങ്ങളും ഞാൻ തിന്നുകയോ കുടിക്കുകയോ ചെയ്യുന്നതിൽ എനിക്ക് കുറ്റബോധം തോന്നാറുണ്ട്. /ent̠e prijappeʈʈajaːɭkkə kaɻikkaːn kaɻijaːt̪t̪a bʱakʂaɳa pad̪aːrt̪t̪ʰaŋŋaɭum/ paːniːjaŋŋaɭum ɲaːn t̪in̪n̪ukajoː kuʈikkukajoː t͡ʃejjun̪n̪at̪il enikkə kut̠t̠aboːd̪ʱam t̪oːn̪n̪aːruɳʈə/.	അതെ /at̪e/	ഇല്ല /illa/
6. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, എന്റെ ശാരീരിക ആരോഗ്യം ശ്രദ്ധിക്കാൻ എനിക്ക് മതിയായ സമയം കിട്ടാറില്ലെന്ന് എനിക്ക് തോന്നാറുണ്ട്. ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam, ent̠e ʃaːɾiːɾika aːɾoːgjam	അതെ /at̪e/	ഇല്ല /illa/

ʃrad̪d̪ʱikkaːn enikkə mat̪ijaːja samajam kiʈʈaːrillen̪n̪ə enikkə t̪oːn̪n̪aːruɳʈə.		
7. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, എനിക്ക് ഇഷ്ടമുള്ള പ്രവർത്തനങ്ങൾക്ക് വേണ്ടത്ര സമയം കിട്ടുന്നില്ല എന്ന് എനിക്ക് തോന്നാറുണ്ട്. en̠te prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam, enikkə iʂʈamuɭɭa praʋart̪t̪anaŋŋaɭkkə ʋeːɳʈat̪ra samajam kiʈʈun̪n̪illa en̪n̪ə enikkə t̪oːn̪n̪aːruɳʈə.	അതെ /at̪e/	ഇല്ല /illa/
8. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, എനിക്ക് വിഷാദം (ടിപ്രെഷൻ) അനുഭവപ്പെടാറുണ്ട്. en̠te prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam enikkə ʋiʂaːd̪am (ʈippreʂan) anubʱaʋappeʈaːruɳʈə.	അതെ /at̪e/	ഇല്ല /illa/
9. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, എനിക്ക് മാനസിക സമ്മർദ്ദം (സ്ട്രെസ്സ്) അനുഭവപ്പെടാറുണ്ട്. en̠te prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam enikkə maːnasika sammard̪d̪am (sʈress) əanubʱaʋappeʈaːruɳʈə.	അതെ /at̪e/	ഇല്ല /illa/
10. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, എനിക്ക് ഉത്കണ്ഠ (ടെൻഷൻ) അനുഭവപ്പെടാറുണ്ട്. /en̠te prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam enikkə ut̪kaɳʈʰa (ʈenʂan) anubʱaʋappeʈaːruɳʈə/.	അതെ /at̪e/	ഇല്ല /illa/
11. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം മറ്റുള്ളവരുടെ സാനിധ്യത്തിൽ എനിക്ക് ചമ്മൽ തോന്നാറുണ്ട്. /en̠te prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ kaːɾaɳam mat̠t̠uɭɭaʋaɾuʈe saːnid̪ʱjat̪t̪il enikkə t͡ʃammal t̪oːn̪n̪aːruɳʈə/.	അതെ /at̪e/	ഇല്ല /illa/

12. എന്റെ പ്രിയപ്പെട്ട ആൾക്ക് അവരുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ എങ്ങനെ അനുഭവപ്പെടുന്നു എന്നതിനെക്കുറിച്ച് ചിന്തിക്കുമ്പോൾ എനിക്ക് വിഷമം തോന്നാറുണ്ട്. /ent̲e prijappeʈʈa aːɭkkə aʋaɾuʈe ʋiɻuŋŋun̲n̲at̲iluɭɭa bud̲d̲ʱimuʈʈukaɭ eŋŋane anubʱaʋappeʈun̲n̲u en̲n̲at̲inekkurit͡ʃ t͡ʃət͡ʃin̲t̲ikkumpoːɭ enikkə ʋiʂamam t̲oːn̲n̲aːruɳʈə/.	അതെ /at̲e/	ഇല്ല /illa/
13. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, ഒരുമിച്ചിരുന്നു ഭക്ഷണം കഴിക്കുന്നതും അതിലെ സാമൂഹികപരമായ വശങ്ങളും കുറഞ്ഞ് വരുന്നതായി എനിക്ക് തോന്നാറുണ്ട്. /ent̲e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̲n̲at̲iluɭɭa bud̲d̲ʱimuʈʈukaɭ kaːɾaɳam, oɾumit͡ʃt͡ʃiɾun̲n̲u bʱakʂaɳam kaɻikkun̲n̲at̲um at̲ile saːmuːɦikapaɾamaːja ʋaʃaŋŋaɭum kuraɲɲə ʋaɾun̲n̲at̲aːji enikkə t̲oːn̲n̲aːruɳʈə/.	അതെ /at̲e/	ഇല്ല /illa/
14. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കാരണം, കുടുംബത്തിൽ നിന്നും സുഹൃത്തുക്കളിൽ നിന്നും ഞാൻ ഒറ്റപ്പെട്ടതായി തോന്നാറുണ്ട്. /ent̲e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̲n̲at̲iluɭɭa bud̲d̲ʱimuʈʈukaɭ kaːɾaɳam kuʈumbat̲t̲il n̲in̲n̲um suɦrɨt̲t̲ukkaɭil n̲in̲n̲um ɲaːn ot̲t̲appeʈʈat̲aːji t̲oːn̲n̲aːruɳʈə/.	അതെ /at̲e/	ഇല്ല /illa/
15. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ കൈകാര്യം ചെയ്യുന്നതിന്റെ ഫലമായി ഞാൻ പെട്ടുപോയതായി എനിക്ക് തോന്നാറുണ്ട്. /ent̲e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̲n̲at̲iluɭɭa bud̲d̲ʱimuʈʈukaɭ kai̯kaːɾjam t͡ʃejjun̲n̲at̲int̲e pʰalamaːji ɲaːn peʈʈupoːjat̲aːji enikkə t̲oːn̲n̲aːruɳʈə/.	അതെ /at̲e/	ഇല്ല /illa/

16. എന്റെ പ്രിയപ്പെട്ടയാളുടെ വിഴുങ്ങുന്നതിലുള്ള ബുദ്ധിമുട്ടുകൾ മെച്ചപ്പെടില്ല എന്ന് ഞാൻ ആശങ്കപ്പെടാറുണ്ട്. /ent̠e prijappeʈʈajaːɭuʈe ʋiɻuŋŋun̪n̪at̪iluɭɭa bud̪d̪ʱimuʈʈukaɭ met͡ʃt͡ʃappeʈilla en̪n̪ə ɲaːn aːʃaŋkappeʈaːruɳʈə/.	അതെ /at̪e/	ഇല്ല /illa/

മുകളിലുള്ള 16 പ്രസ്താവനകളിൽ, ഏതാണ് നിങ്ങളെ ഏറ്റവും അലട്ടുന്നത്? നമ്പർ

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/mukaɭiluɭɭa 16 prast̪aːʋanakaɭil, eːt̪aːɳə n̪iŋŋaɭe eːt̠t̠aʋum alaʈʈun̪n̪at̪ə/? /n̪ampar/

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