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**Creation and Initial Validation of the  
Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES)  
Screening Tool**

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## **Abstract**

**Purpose:** Dysphagia is a debilitating condition with widespread consequences. Previous research has revealed dysphagia to be an independent predictor of caregiver burden. However, there is currently no systematic method of screening for or identifying dysphagia-related caregiver burden. The aim of this study was to develop a set of questions for a dysphagia-related caregiver burden screening tool, the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES), and pilot the tool to establish preliminary validity and reliability.

**Methods:** The questionnaire was developed through an iterative process by a team of clinical researchers with expertise in dysphagia, dysphagia-related and general caregiver burden, and questionnaire design. A heterogenous group of 26 family caregivers of people with dysphagia completed the CARES, along with the Eating Assessment Tool (EAT-10), IDDSI Functional Diet Scale (IDDSI-FDS), and Zarit Burden Interview (ZBI). Information on construct validity, item fit, convergent validity, internal consistency, and reliability were determined via Rasch analysis model testing, Cronbach's alpha, and Spearman's Rho calculations.

**Results:** The final CARES questionnaire contained 26 items divided across two subscales. The majority of the questionnaire items fit the model, there was evidence of internal consistency across both subscales, and there were significant relationships between dysphagia-specific burden (CARES) and perceived swallowing impairment (EAT-10), general caregiver burden (ZBI), and diet restrictiveness (IDDSI-FDS).

**Conclusions:** Results from the current study provide initial support for the validity and reliability of the CARES as a screening tool for dysphagia-related burden, particularly among caregivers of adults with swallowing difficulties. While continued testing is needed across larger groups of specific patient populations, it is clear that the CARES can initiate structured conversations about

dysphagia-related caregiver burden by identifying potential sources of stress and/or contention.

This will allow clinicians to then identify concrete methods of reducing burden and make appropriate referrals, ultimately improving patient care.

## **Introduction**

For many patients, a diagnosis of dysphagia diagnosis can be debilitating (Jones et al., 2018). Amongst other worries and stressors, many of these patients experience pain, fear, and frustration when they eat (Martino et al., 2010; Seshadri et al., 2018; Tsujimura & Inoue, 2020), lack enjoyment in eating (Ganzer et al., 2015; Moloney & Walshe, 2018; Nund et al., 2014b), worry about how to prepare modified diets and/or tube-feeds (Leow et al., 2010), experience weight loss and sarcopenia (Carrión et al., 2017; Yoshimura et al., 2018), and are concerned as to whether and how they are able to eat outside of the home (Ekberg et al., 2002; Howells et al., 2020; Seshadri et al., 2018). This has been shown to result in anxiety and depression (Ekberg et al., 2002; Verdonschot et al., 2017), social isolation (Ekberg et al., 2002; Moloney & Walshe, 2018; Seshadri et al., 2018), and overall reduced quality of life (Jones et al., 2018; Leow et al., 2010; Yi et al., 2019).

Informal caregivers, often family or other individuals providing unpaid and ongoing assistance (e.g., Roth et al., 2015), support many of these patients in order to reduce associated stresses and anxieties and promote a higher quality of life. However, previous research has indicated that as a consequence, family members of patients with dysphagia suffer from caregiver burden (Johansson & Johansson, 2009; Miller et al., 2006; Namasivayam-MacDonald & Shune, 2020; Namasivayam-MacDonald & Shune, 2018; Nund et al., 2016; Nund et al., 2014a; Patterson et al., 2013; Penner et al., 2012; Shune & Namasivayam-MacDonald, 2020). In helping with meal planning, meal preparation, feeding and other mealtime-related tasks, caregivers struggle with “negotiating a new normal” and some report fear and anxiety related to ensuring their care recipient eats and drinks safely (Johansson & Johansson, 2009; Nund et al., 2016; Nund et al., 2014a; Patterson et al., 2013; Penner et al., 2012). Some caregivers may be

managing tube feedings and these caregivers report feeling inadequately prepared to manage tube-feeding, increasing caregiver stress and anxiety as well as the risk for tube-related complications (Namasivayam-MacDonald & Shune, 2018; Penner et al., 2012). Research has also revealed that caregivers have decreased social involvement outside of the home and feel like meals inside the home lack a feeling of togetherness (Johansson & Johansson, 2009; Nund et al., 2016; Nund et al., 2014a; Patterson et al., 2013; Penner et al., 2012). More recent research has looked at the type and extent of burden experienced by different types of caregivers. Specifically, spousal caregivers have been found to experience higher levels of emotional burden when their care recipient has swallowing difficulties, with nearly 70% of spouses rating this burden as moderate to severe (Shune & Namasivayam-MacDonald, 2020). Another study analyzing type and extent of burden in adults caring for aging parents with swallowing impairments found that these caregivers reported both emotional and physical burden, with at least 40% of caregivers reporting moderate to severe levels of burden (Namasivayam-MacDonald & Shune, 2020).

The costs associated with caregiving are often high, with primary stressors (e.g., duration of caregiving, functional disabilities of care recipient) and secondary stressors (e.g., finances, family conflict) negatively impacting the physical health and mental well-being of caregivers (Schulz & Sherwood, 2008). Such burden is associated with increased risk of comorbidities, including depression, anxiety, stress, fatigue, and decreased overall immunity, as well as reduced quality of life across physical, psychological, and social domains (Allen et al., 2017; Dawood, 2016; de Wit et al., 2018; Jacob et al., 2020; Kiecolt-Glaser et al., 1991; Liu et al., 2017; Schulz et al., 1997; Schulz et al., 1995). Informal caregivers experiencing mental or emotional strain also have increased risk of mortality as compared to non-caregivers (Schulz & Beach, 1999). Unfortunately, the consequences of burden extend beyond the caregivers themselves. As their

own health and well-being decreases, these caregivers may be less able to provide quality care, which can negatively impact care recipient health, requiring a greater degree of care (Torti et al., 2004; Wolff et al., 2016). Indeed, increased caregiver burden and distress has been associated with worsened care recipient physical, behavioral, and psychological health outcomes, increased risk of care recipient institutionalization, and decreased care recipient quality of life (Bilotta et al., 2010; Stall et al., 2019).

In light of the clear consequences of caregiver burden across populations, reducing such burden is a health priority and should be considered within the comprehensive dysphagia management model (Shune & Namasivayam-MacDonald, in press). Current dysphagia practice guidelines recommend screenings be completed by healthcare professionals in order to identify those individuals most at risk who should undergo further assessment by a speech-language pathologist (Suiter et al., 2020). Screening is indeed a cornerstone of preventative medicine more broadly, aimed at reducing morbidity and mortality by identifying disease during an early, and perhaps pre-symptomatic, stage (Maxim et al., 2014; Wilson et al., 1968). Screening can also reduce morbidity or mortality among other persons who could be impacted by the disease (Maxim et al., 2014). Early identification of dysphagia-related caregiver burden can ultimately lead to earlier intervention, which can translate into improved health and well-being for both caregivers and their care recipients. In order to achieve the maximal and most efficient benefit, the screening tool should be quick, easy to use, and translatable across multiple populations.

Yet, despite the growing evidence surrounding dysphagia-related caregiver burden and the clear consequences of this burden, there currently are limited ways in which to objectively measure or screen for caregivers' needs related to helping manage a swallowing impairment. This decreases the ability to provide focused and person-centered interventions aimed at

reducing this burden. Many commonly used caregiver burden assessment tools, such as the Zarit Burden Interview (Zarit et al., 1980; Zarit et al., 1986), the Caregiver Burden Inventory (Novak & Guest, 1989), the Modified Caregiver Strain Index (Robinson, 1983; Thornton & Travis, 2003), and the Caregiver Self-Assessment Questionnaire (Epstein-Lubow et al., 2010), do not specifically address swallowing challenges or related burden. These tools identify general feelings of burden and stress, including role captivity, overload, relational deprivation, competence, personal gain, coping, family beliefs and conflict, job conflicts, and financial disruption. While they may help to initiate a referral to a counsellor, social worker or psychologist, it would be difficult for a clinician specializing in swallowing impairments to pinpoint dysphagia's impact on a caregiver and clear-cut methods to support the caregiver who may be feeling overwhelmed. The Feeding/Swallowing Impact Survey (FS-IS) (Lefton-Greif et al., 2014) is one instrument that was specifically designed to measure and improve understanding of caregiver issues related to caring for children. This 18-item tool is validated and was developed based on caregiver input and consensus of clinical experts who care for children with feeding/swallowing problems. It broadly covers three categories: (1) problems carrying out daily activities; (2) problems with worrying; and (3) problems feeding the child. However, the FS-IS was developed for caregivers of very young children (median sample age 14 months, IQR 7 to 35 months), using a sample from a single outpatient clinic, and may not be translatable to other caregivers of individuals with dysphagia. Further, the FS-IS was developed to measure the impact of a child's feeding/swallowing problems on caregiver health-related quality of life, resulting in a multidimensional, comprehensive assessment tool.

The purpose of this study was to develop and test a simple screening tool to identify dysphagia-related caregiver burden and to determine whether the tool could be used as a

universal screener across multiple populations. Based on a Rasch analysis, it was hypothesized that the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) questionnaire would be reliable based on internal consistency and valid based on item fit. Further, to test validity, it was hypothesized that (a) caregivers who experience greater dysphagia-related burden were caring for individuals with more severe dysphagia and these caregivers experienced greater general burden; and (b) increased dysphagia-related caregiver burden was related to behavioral and functional changes associated with increased diet restrictiveness among care recipients.

### **Methods**

This investigation was approved by the Institutional Review Boards at the University of Oregon and Adelphi University. This was an online survey among caregivers of individuals with dysphagia.

### **Sample**

A primary goal of the current study was to develop a universal screening tool for dysphagia-related caregiver burden. Thus, in order to capture the perspectives of caregivers of individuals across the lifespan with a variety of etiologies, inclusion criteria were broad. Caregivers were eligible to participate if they answered affirmative to the following question: “Are you the caregiver of a family member who you are living with?”. To disseminate the survey, an invitation and survey link was sent to clinicians via the American Speech-Language-Hearing Association’s Special Interest Group 13 – Swallowing and Swallowing Disorders (Dysphagia) listserv, as well as through Facebook groups, such as the Medical SLP Forum and the Dysphagia Squad. Clinicians were asked to pass the survey link to patients and clients. The



invitation and survey link were also disseminated through dysphagia-focused support groups, such as the National Foundation of Swallowing Disorders' online Facebook support groups.

## **Measures**

**Participant demographic information.** Basic demographic information collected included information about both the caregiver and care recipient. Questions about the caregiver included age, gender, and relationship to care recipient. Questions about the care recipient included age, information about swallowing difficulties, dysphagia diagnosis status, and other medical conditions requiring need for care.

**Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES).** The initial CARES questionnaire was developed through an iterative process. First, two speech-language pathology experts in dysphagia and dysphagia-related caregiver burden (ANM, SS) each independently generated a comprehensive list of potential questions based on the previous burden literature and their clinical expertise. The resulting list of 55 potential questions was reviewed for overlaps or similar ideas; these questions were then condensed. Items that appeared on only a single list were discussed until consensus was reached as to whether to include them in the first draft of the questionnaire. The draft questionnaire was next independently reviewed for initial face, content, and construct validity by two experts in general caregiver burden and questionnaire design (BR, SZ). Team members were also asked to rank their top 15 questions that they felt were most valuable, as well as list any questions that were not included, but they felt should be. These comments were reviewed by both questionnaire authors and integrated with more general theories related to caregiver burden and family systems, including the biopsychosocial-spiritual model (Rolland, 1994, 2017), and then compared to other caregiver burden questionnaires, such as the Zarit Burden Interview (Zarit et al., 1980; Zarit et al., 1986),

and the FS-IS (Lefton-Greif et al., 2014). Questionnaire structure was also reviewed. The potential question items appeared to cluster around two separate topics: items related to changes that have occurred as a result of the dysphagia and caregivers' appraisal of those changes and items related to caregivers' subjective experience of how dysphagia has impacted their lives. The questionnaire was then revised accordingly, including modifications to question wording, question inclusion, and overall questionnaire structure, and this process continued iteratively until a consensus was reached.

The final CARES questionnaire (see Tables 1 and 2) contained 26 items divided across two subscales: Part A – Checklist of Behavioral and Functional Changes (10 items) and Part B – Measures of Subjective Caregiver Stress (16 items). The Measures of Subjective Caregiver Stress subscale also contained an additional “other” item option, allowing participants to add additional scenarios not covered by the statements listed. Part A was scored out of 10 points and Part B was scored out of 16 points (1 point for every ‘yes’ response), with higher scores indicating a higher degree of dysphagia-related caregiver burden for both subscales.

Participants were also provided the opportunity to comment on the CARES questionnaire via guided questions regarding the relevance of the topics covered and item clarity. Specifically, participants were asked when thinking about the questions on the dysphagia-related caregiver burden tool whether: (a) there were any topics that were not covered regarding the burden felt related to the care recipient's swallowing difficulties; (b) there were any questions that were confusing or difficult to understand; (c) there were any questions that were redundant; (d) the response choices were adequate (i.e., easily able to respond based on choices provided); and (e) all the questions addressed caregiver burden related to a loved one's swallowing difficulties.

Participants were also provided with an open-ended comments box to share other comments or thoughts related to the tool that were not covered elsewhere.

**The Eating Assessment Tool (EAT-10).** The EAT-10 (Belafsky et al., 2008) is a validated, 10-item symptom-specific swallowing outcomes tool designed to quantify perceived swallowing impairment. The goal is to understand the extent to which patients experience a series of problems, such as losing weight due to a swallowing impairment, pain while swallowing, coughing when eating, and ability to go out to eat. The EAT-10 uses Likert scale responses to determine if each problem statement results in “no problem” (score of 0) up to a “severe problem” (score of 4). A score greater than 3 is suggested to indicate risk of dysphagia. It is generally completed by patients, but for the purposes of the current study it was used to assess the caregiver’s perception of if and how the swallowing difficulties impacted their care recipient’s quality of life. Previous research suggests that proxies can reliably report on observable symptoms (McPherson & Addington-Hall, 2003; Oczkowski & O’Donnell, 2010), such as weight loss, coughing, and ability to eat outside of the home. Further, pain and increased effort are often noticeable, and some other issues are likely to be discussed by the care recipient and the caregivers, such as the pleasure of eating, mealtime-related stress, and food sticking in the throat. Therefore, it is likely that caregivers are able to accurately report on signs, symptoms and consequences of the care recipient’s dysphagia.

**The IDDSI Functional Diet Scale (IDDSI-FDS).** The IDDSI-FDS (Steele et al., 2018) is a valid tool that was created to capture degree of diet texture restriction in reference to the International Dysphagia Diet Standardisation Initiative (IDDSI) framework. It is intended to be an accompaniment to the IDDSI diet texture prescription. Scores range from 0 to 8, where a score of 8 indicates that the patient is on an unmodified diet, and scores close to 8 indicate that

the patient is on a relatively unrestricted diet. As scores approach 0, diets become more restricted, and a score of 0 indicates that the patient cannot take anything by mouth. Scores are derived using a matrix similar to a mileage chart such that scores correspond to the number of IDDSI levels on the framework that the diet spans. For example, if a patient is prescribed an IDDSI Level 0 (thin liquids) for their drink prescription and IDDSI Level 6 (soft and bite-sized solids) for their food prescription, it is assumed that they can consume anything from Level 0 to Level 6, for a total of 7 level. Therefore, their IDDSI-FDS score is 7.

**The Zarit Burden Interview (ZBI).** The 22-item Zarit Burden Interview (Zarit et al., 1980; Zarit et al., 1986) is a valid and reliable self-report measure designed to quantify general caregiver burden, incorporating both objective and subjective burden. The ZBI queries common areas of concern including those related to finances, health, social life, and interpersonal relationships and explores both personal and role strain. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (never) to 4 (nearly always). Total scores can range from 0 to 88, and higher scores are associated with increased caregiver burden. This tool is commonly used in both clinical and research settings across a diverse range of caregiver and patient populations.

### **Data Collection**

Potential participants accessed the study materials via a Qualtrics survey. A paragraph describing the minimum disclosure for informed consent was provided at the beginning of the survey and participants indicated their consent to participate by continuing with the survey. All study activities took approximately 20-25 minutes to complete, and all responses were collected anonymously. The survey remained open for three months total.

## **Data Analysis**

Information on internal consistency and the fit of the items to the model was evaluated using Rasch analysis model testing with the Winsteps statistical program. The Rasch model, a type of item response theory, is a psychometric model for analyzing measurement scales that allows for the identification and reduction of redundancy in items and scoring levels to yield a valid and simple measure (Smith & Smith, 2004). The Rasch analysis provides INFIT and OUTFIT statistics for each item, which indicate where one should consider either deleting, rescore, or rewording an item. These were evaluated and considered acceptable if they were in the range of 0.5 to 1.5 (Linacre, 2010). A value of less than 0.5 indicates that the item may be redundant and not provide additional information beyond the rest of the items on the scale. A value of greater than 1.5 indicates a lack of homogeneity, suggesting that the item does not define the same construct as the rest of the items in the questionnaire, that the item is poorly constructed or misunderstood, or that the item is ambiguously defined (Wright & Linacre, 1994). Mapping of the items across each CARES subscale was also considered to establish if the items comprehensively addressed the concept of dysphagia-related caregiver burden, ensuring spread across the full range of the concept (i.e., severity). While the initial questionnaire was designed using a Likert rating scale for item responses, initial analyses revealed better item spread using a dichotomous “Yes/No” response system; either ‘yes’ the caregiver was experiencing the burden described or ‘no’ they were not. This revised scoring was subsequently adopted for use and all results presented below are based on this questionnaire version.

An index of reliability based on Rasch measurement was also performed, which considers both the person separation reliability index (i.e., how well a measure can discriminate people based on their outcome expectations) and the item separation index (i.e., how well items

can be discriminated from one another on the basis of their difficulty). The index of reliability is equivalent to an estimate of internal consistency and Cronbach's alpha. An alpha coefficient of .70 or greater is generally considered to be acceptable (DeVellis, 2012). A traditional alpha coefficient was also calculated using SPSS (Version 26, IBM Corporation, Armonk, NY).

Bivariate correlations (Spearman's Rho) were performed to evaluate convergent validity of the CARES overall and subscale scores to test the hypotheses that caregivers who experienced greater dysphagia-related burden were caring for individuals with more severe dysphagia and diet restrictiveness and that these caregivers also experienced greater general burden based on EAT-10, IDDSI-FDS and ZBI. To correct for multiple comparisons, the Holm-Bonferroni method was applied.

## **Results**

A total of 40 participants completed the survey. Given the aim to develop a tool specifically to screen for dysphagia-related caregiver burden, and to differentiate burden among caregivers of individuals with known dysphagia, participants were excluded if their care recipient did not have any difficulties swallowing. For example, an individual receiving a burden score of "0," indicating no burden, due to their care recipient not having dysphagia would be fundamentally different than an individual receiving a burden score of "0" despite their care recipient having dysphagia. In total, 6 surveys were excluded due to care recipients not having any difficulties swallowing. Another 8 were excluded due to the caregiver not completing any of the CARES portion of the survey. This resulted in the data from 26 caregivers (65% of completed surveys) being used in the analyses.

The participants in the study represented a heterogeneous group of caregivers (see Table 3). Caregivers were primarily middle-aged ( $M = 49.31$  years,  $SD = 17.04$ , range 25-77) females

(92.3%) providing care to their child (42.3%), partner/spouse (34.6%), or parent (19.2%). The care recipients ranged in age, with approximately 35% being children under the age of 18 and 65% adults. Of the adult care recipients that had ages reported, a majority were older adults (over the age of 65; 56.3%). All care recipients experienced swallowing difficulties according to their caregivers and the majority also had a diagnosis of dysphagia (88.5%). The care recipients had a wide range of medical conditions that contributed to their need for care, including neurologic impairment (e.g., dementia, Parkinson's disease, facial palsy), cardiac-related conditions (e.g., cardiovascular disease, stroke), respiratory conditions (e.g., asthma, pneumonia, bronchiectasis, aspiration pneumonia), structural abnormalities (e.g., laryngeal cleft, vocal cord paralysis), cancer (e.g., squamous cell cancer, laryngeal cancer, metastatic cancer of unknown etiology), and congenital conditions (e.g., Dandy Walker Syndrome, tracheomalacia, tracheobronchomalacia).

Summary scores for CARES, the ZBI, EAT-10 and IDDSI-FDS can be found in Table 3. Scores on Part A of the CARES ranged from 0 to 10, and scores on Part B of the CARES ranged from 4 to 16, with overall scores ranging from 4 to 24. Eighty-eight percent of respondents reported caregiver burden, as per the ZBI (i.e., scores >20 indicating at least mild burden (Hébert et al., 2000; Stagg & Lerner, 2015)), with scores ranging from 3 to 63, out of a total of 88 possible points. Higher scores are indicative of more burden. All of the caregivers (100%) also reported presence of dysphagia-related signs and symptoms, as per the EAT-10 (i.e., scores >3, with a maximum of 40 points), with scores ranging from 6 to 40. Scores on the IDDSI-FDS can range from 0 to 8, with a score of 0 indicating that the person is on a non-oral diet and a score of 8 indicating that the person requires no diet modifications. Most care recipients (92%) were on

modified a diet, with a score of 6 on the IDDSI-FDS being most common ( $n = 7$ ) and all possible scores being represented in the sample.

### **Validity Testing**

The Rasch analysis provided information about the fit of the items to the model and how well the tool was able to differentiate those high or low in dysphagia-related caregiver burden. Fit statistics are presented in Tables 4 and 5 for Part A and Part B of the CARES, respectively. As shown in Table 4, INFIT statistics for Part A ranged from 0.81 (item 2) to 1.17 (item 9) and OUTFIT statistics ranged from 0.72 (item 2) to 1.11 (item 9). As shown in Table 5, INFIT statistics for Part B ranged from 0.59 (item 15) to 1.49 (item 5) and OUTFIT statistics ranged from .22 (item 9) to 2.37 (item 10). Of the 26 items across the two scales, all items had INFIT values within the acceptable range and 22 of 26 had OUTFIT values within the acceptable range. The exceptions were items 5, 9, 10, and 15 on Part B.

Item mapping (Tables 6 and 7) provided additional information regarding the difficulty of these items and how well the items spread across the concept of burden. The items that were easiest for participants to agree with and endorse included “Extra time is required for mealtimes” and “Managing my loved one’s swallowing difficulties takes away from other things I would prefer to be doing” (Part A), and “I am scared that my love one will choke” and “I feel stressed” (Part B). The items that were most difficult for participants to agree with and endorse included “Other family members disagree with me about how to best manage my loved one’s swallowing difficulties” and “I avoid eating or drinking items that my loved one cannot have” (Part A), and “I feel like my loved one does not do as much as they can to help with their swallowing difficulties” (Part B).



There was also evidence of validity based on the bivariate correlations between the CARES, EAT-10, IDDSI-FDS, and ZBI (see Table 8). Caregivers reported dysphagia-related burden, as measured by all CARES scores (Part A, Part B and total score), was positively associated with the EAT-10 and ZBI, such that increased dysphagia-related burden was associated with increased perceived dysphagia severity and increased general caregiver burden. Further, Part A of the CARES (Checklist of Behavioral and Functional Changes) was negatively associated with IDDSI-FDS, such that increased dysphagia-related caregiver burden related to behavioral and functional changes was associated with increased diet restrictiveness.

### **Reliability**

There was evidence of internal consistency for Part B of the CARES with a Cronbach's alpha value of 0.77. The Rasch analysis provided similar estimates with a person separation index of 1.66 and a reliability score of 0.73, and an item separation index of 2.25 with a reliability score of 0.83. Values for Part A were slightly lower, with a Cronbach's alpha value of 0.65 and a person separation index of 1.29 and reliability score of 0.62. The item reliability score for Part A was lower than recommended at 0.45 (separation index 0.90). Cronbach's alpha for the total Scale was 0.79.

### **Qualitative feedback**

Twelve respondents indicated that there were topics that were not covered in the tool, although not all feedback described topics relevant to dysphagia-specific burden. Two of the nine caregivers of children with dysphagia stated that they felt the tool did not seem to fit as much with the experiences of providing care specifically for infants with dysphagia, as the demands differ. Three caregivers felt that the topic of financial burdens was not addressed within the CARES. One of these caregivers stated that they had to give up their job in order to provide care

for their family member, and now they both are financially dependent on a third party. Another caregiver included that there was “financial burden of special preparations” of meals. Tube feeding was another topic that two caregivers felt was not covered by the survey, particularly surrounding making decisions about and managing the feeding tubes. Three caregivers felt that the amount of time spent caregiving was adequately captured within the tool. Two of the three shared that they spend a significant amount of time taking their care recipient to medical appointments, which added to their burden. The third caregiver felt that a lot of time was being spent on meal preparation. Four other caregivers also mentioned the challenges surrounding mealtimes, including knowing what to allow their family member to eat, the difficulties surrounding meal planning, as well as having to change their diet so that the caregiver and care recipient can eat together. Navigating the healthcare system was also cited by two respondents as a source of burden that was not captured within the tool. Lastly, two caregivers noted that the CARES did not capture change in burden over time, stating that their burden has decreased in the past year. The remaining caregivers either indicated that all topics related to the dysphagia-related burden they experience were covered on the CARES (n = 10) or did not respond to the question (n = 4).

Further, one respondent noted that the questions regarding dependency were confusing to caregivers of children given that children are naturally more dependent. Another respondent felt that the format of some questions was inappropriate. For example, the “Likert rating scale did not always adequately allow for responses to questions about feelings”. The remaining caregivers either indicated that the questions were not confusing or difficult to understand (n = 22) or did not respond (n = 2). None of the respondents reported that the questions were redundant.

When caregivers were asked if response choices were adequate within the CARES tool, one caregiver reported that it was “difficult to answer [questions] about changes in the last month” because they have experienced no changes, despite feeling burdened. The remaining respondents either reported that response choices were adequate (n = 17), reported that response choices were not all adequate but did not provide any qualitative feedback (n = 5), or did not respond (n = 3). Lastly caregivers were asked if all questions addressed dysphagia-related caregiver burden. Fifteen respondents indicated “yes”. One respondent stated that the tool does not address abuse, while another felt that it does not discuss support systems that ultimately influence amount of burden. Yet another respondent stated: “We are nearly three years in to my husband’s PEG tube use - like grief, many of the questions are ‘stage’ questions and don’t necessarily apply now to me, but would have early on in this journey”. A fourth caregiver wrote: “The dysphagia is only one part of the larger burden of caring for someone after a devastating stroke that has affected everything to do with how muscles work together. Speech, mobility, swallowing and mentation have ALL changed and become quite stressful, and I cannot totally separate out caregiving burdens ONLY based of dysphagia. It’s a complex package deal.”

Overall, the majority of caregivers chose not to respond within the open-ended free-text box. Those who chose to respond responded positively to the CARES tool, re-emphasizing the burden they experience, and/or provided additional suggestions for improvement.

### **Discussion**

The purpose of this study was to develop and pilot test the CARES questionnaire as a screening tool for dysphagia-related caregiver burden. Results from the current study provide initial support for the validity and reliability of this measure across a heterogenous group of individuals providing care for individuals with dysphagia. More specifically, the majority of the

items fit the model based on Rasch analysis, there was evidence of internal consistency, and, as expected, there were significant relationships between dysphagia-specific burden (CARES) and perceived swallowing impairment (EAT-10), general caregiver burden (ZBI), and diet restrictiveness (IDDSI-FDS). Further, the results also provided information to inform revisions in order to strengthen the tool.

Overall, problems with OUTFIT, or ‘outlier-sensitive fit’, tend to be less of a threat to measurement than INFIT, or ‘inlier-sensitive fit’ (Linacre, 2012). All of the tested items had INFIT values within the acceptable range, supporting that the items fit the measurement model. Further, all of the items on Part A had OUTFIT values within the acceptable range. However, four items from Part B had OUTFIT statistics outside of this range. Item 9 (“I feel stressed”) and item 15 (“I feel trapped as a result of managing my loved one’s swallowing difficulties”) had OUTFIT statistics less than 0.5, suggesting these items were redundant or described experiences (e.g., stress) that are common across this population. Item 5 (“I feel guilty eating or drinking items that my loved one cannot have”) had an OUTFIT statistic greater than 1.5, suggesting this item may not map onto the concept of dysphagia-related burden or perform in the way in which one would expect, or that this item may have been poorly understood. Item 10 (“I feel anxious”) had an OUTFIT statistic greater than 2, which similarly suggests potential problems with this item. Notably, such an extreme value can be caused by only one or two observations. It is recommended that these items be retained in the measure and further tested in a larger sample of caregivers.

In the absence of a current gold standard for measuring dysphagia-related caregiver burden, convergent validity was evaluated using a measure of more global caregiver burden and two potential proxy measures of dysphagia severity (caregiver-perceived swallowing impairment

via the EAT-10 and diet restrictiveness via the IDDSI-FDS). Increased global caregiver burden and increased perceived swallowing impairment were significantly associated with increased dysphagia-specific burden across all CARES scores, with the strength of the relationships ranging from moderate to strong. Dysphagia-specific burden as measured by Part A of the CARES was also moderately correlated with diet restrictiveness (i.e., increased burden, increased dietary restrictions). While the directions of these relationships were as expected, the particular strength of the relationship between the CARES and ZBI is worth noting. Nearly all of the caregivers who participated in the current study were experiencing caregiver burden in general, which was subsequently strongly correlated with their level of dysphagia-specific burden. This suggests the need to further delineate the contributions of dysphagia-related burden to overall caregiver burden, as has been previously suggested (Namasivayam-MacDonald & Shune, 2020; Shune & Namasivayam-MacDonald, 2020). However, this also suggests the need to continue to tease out burden related to the disease itself and burden related to the dysphagia, which was revealed in the qualitative comments provided by a few of the participants.

There was sufficient evidence of internal consistency and reliability for Part B of the CARES and the value of the Cronbach's alpha for Part A was near the generally recommended 0.7 level. However, the item reliability score and separation index for Part A were low. This set of measures is particularly susceptible to a small sample size and thus these lower values may suggest that the sample size was not large enough to confirm the item difficulty hierarchy rather than indicating an underlying issue with the measurement tool itself.

While a majority of participants indicated that questions were clear and the items related to dysphagia-related burden, nearly half of the participants indicated at least one aspect of care or burden that was not covered in the tool, supporting the need for continued tool refinement and

testing. However, it is important to note that only a small proportion of participants made a variety of specific suggestions, such as the fact that the tool did not address financial burden, was not fully applicable to pediatric caregivers, did not capture the challenges associated with tube-feeding, did not include the challenges associated with navigating the healthcare system, did not capture changes over time, and/or did not capture how they spent their time. While these comments are appreciated, we were wary of making significant changes or additions based on the suggestions of only a few participants. Our ultimate goal was not to develop a comprehensive measure of burden, but rather to develop a universal screening tool for dysphagia-related burden that was simple and fast to administer within a clinical setting, and would give the administering clinician an idea of the areas requiring support and need for further assessment. Therefore, adding additional items based on limited information detracts from the goal of ensuring the tool can be completed quickly. Further, given that our tool will most likely be administered by healthcare professionals focused on swallowing impairments, we worked to include items that were specific to dysphagia. Topics like navigating the healthcare system and capturing how time is spent, while important to help support caregivers, are not unique to dysphagia. Relatedly, previous work has revealed dysphagia to be an independent predictor of emotional and/or physical burden, however it was not an independent predictor of financial burden (Namasivayam-MacDonald & Shune, 2020; Shune & Namasivayam-MacDonald, 2020). Thus, it is likely that some of the topics “missed” in the CARES questionnaire, such as financial impact, may be more related to the overall disease process than dysphagia itself. We also attempted to word items within the CARES tool in such a way that they would apply to a wide range of caregivers of patients with dysphagia, including those who require tube feeds. Future research should specifically recruit caregivers who have to deal with a loved one’s tube feeds and

determine if they feel that items within the CARES capture their dysphagia-related caregiving experiences. It is plausible that the experience of those caregivers of individuals requiring tube feedings is different enough that it would require a more specific tool in order to adequately capture the associated burdens. Future studies with much larger clinical samples will be required to ascertain if the aforementioned additions or modifications are required.

Other caregiver burden screening and assessment tools commonly ask caregivers to think about their experiences over the last month. This is presumably to help orient the caregiver and allow them to recall events within a reasonable period of time. However, this prevents one from obtaining information about changes over time. The intention was that the CARES would act similarly and evaluate burden at a single point in time. As inclusion criteria for the current study were broad, it is likely that the tool may be less beneficial for caregivers at certain points in the recovery process (e.g., acute severe dysphagia that has resolved to very mild chronic dysphagia) – this was certainly reflected in the qualitative comments of a few participants. Thus, if a clinician is interested in capturing change in dysphagia-related burden, which is likely to occur with recovery and/or disease progression, the CARES tool could be administered by clinicians at set time points to determine how burden is improving or worsening with time.

We also appreciate that our tool may not resonate as much with caregivers of children with dysphagia. A small subset of the respondents caring for children (n = 2 out of 9 total) indicated that the tool may not adequately represent their unique challenges, particularly in terms of providing care for infants. Indeed the feeding and swallowing experience for infants who never had volitional control over their eating, and thus always presented with a higher degree of dependency, may yield different responses related to caregiver-perceived burden. The FS-IS (Lefton-Greif et al., 2014) may offer a more robust measure of the specific issues associated with

caring for a child with dysphagia as compared to the CARES, particularly for those caring for infants with dysphagia. Future work in the pediatric realm should focus on continued validation of the FS-IS to determine whether the FS-IS adequately captures the burden experienced by caregivers of children with dysphagia across the age, dependency, and acuity spectrum. Depending on the findings, it may also be beneficial to examine the FS-IS in tandem with a modified version of the CARES geared more toward older, more independent pediatric populations, particularly for caregivers of older children with acquired dysphagia.

Lastly, it is important to note that the CARES screening tool is not intended to be used in isolation or in place of conversation with caregivers. Each caregiver's experience and needs are unique. Previous research supports that merely asking caregivers how they are doing and tailoring communication to the caregiver is immensely important for increased engagement, information processing, and self-efficacy (Longacre et al., 2015). Thus, the CARES is intended to give clinicians a structured opportunity to start conversations about dysphagia-related caregiver burden by identifying potential sources of stress and/or contention. Once the sources are identified, clinicians can then facilitate the identification of concrete methods of reducing burden (e.g., increased education/training) or making appropriate referrals as needed (e.g., social work, psychology, medical family therapy).

### **Study Limitations**

A number of study limitations are important to consider. Given the nature of recruiting primarily through online and social media platforms, it was not possible to quantify reach or estimate response rates. Thus, it was also not possible to characterize the sample of non-participants, increasing the risk of non-response bias. For example, it is plausible that those individuals experiencing the highest rates of caregiver burden would be least likely to participate



in a voluntary research study. The sample size of this study as a validation trial was also relatively small. However, based on participants' comments, they appeared to be engaged in the process and approached the scale in a thoughtful way. Further, the primary objective of the current pilot study was achieved; that is, to develop the tool and complete preliminary validation, with an emphasis on determining the viability of the CARES as a universal screening tool. While a heterogeneous group of caregivers was purposefully targeted, it became clear from the qualitative feedback that the tool may be more accurately capturing the experience of certain groups of caregivers as compared to others (e.g., based on age of care recipient, based on acuity of care recipient's medical condition). Thus, while all data was included in the initial pilot validation, continued testing of the CARES among larger samples of specific adult patient populations will be necessary for continued refinement, and caregivers of children will be excluded. For determining convergent validity of this initial version of the CARES, estimates of swallowing status (i.e., EAT-10 and IDDSI-FDS) based on proxy report were used. While the significant associations support the validity of the tool (e.g., increased perceived impairment was associated with increased dysphagia-specific burden), the current results do not consider (a) objective measures of swallowing function, and (b) care recipient perceived measures of swallowing function. Such information will be crucial for identifying potential predictors of dysphagia-related caregiver burden and targets for caregiver-focused interventions.

### **Future Directions and Conclusion**

In conclusion, the CARES screening tool is a valid, easy-to-administer, and simple to score, 26-item checklist that is able to detect dysphagia-related burden, particularly among caregivers of adults with swallowing difficulties. It is significantly correlated with measures of general burden and dysphagia severity. The CARES will allow both clinicians and researchers to

improve their understanding of dysphagia-related caregiver burden. In doing so, they can work to support caregivers, which will ultimately improve the health and quality of life of patients around the world with dysphagia. Future research should focus on confirming the clinical utility of the CARES through the assessment of validity and reliability via larger groups of specific patient populations. Future work will also focus on establishing cut-off scores to determine presence of dysphagia-related burden, in line with the goals of disease screening. The current study, however, ultimately lays the foundation for initial evidence to support the reliability and validity of the CARES screening tool, which has important implications for thousands of patients and their caregivers around the globe.

### Acknowledgements

We would like to thank David Bayne and the members of the Optimizing Swallowing and Eating for the Elderly Lab for their assistance with naming the CARES questionnaire.

**Table 1.** The CARES Questionnaire, Part A – Checklist of Behavioral and Functional Changes

*For each of the following statements, please think specifically about your loved one/care recipient’s eating or swallowing difficulties **during the past month**. Has the situation described in the statement bothered **you**? If it has not occurred, please indicate “N/A”.*

**In the past month, has this situation bothered you?**

Because of my loved one’s swallowing difficulties, extra time is required for mealtimes (e.g., finding appropriate foods, cooking meals, preparing tube feedings, watching my loved one eat/drink).	<b>YES</b>	<b>NO</b>	<b>N/A</b>
Because of my loved one’s swallowing difficulties, my mealtime- and nutrition-related responsibilities have increased (e.g., related to shopping, cooking, tube feeding).	<b>YES</b>	<b>NO</b>	<b>N/A</b>
Because of my loved one’s swallowing difficulties, the costs associated with their nutrition-related needs have increased (e.g., supplies for tube feedings, thickening products or thickened liquids, supplements).	<b>YES</b>	<b>NO</b>	<b>N/A</b>
Other family members disagree with me about how to best manage my loved one’s swallowing difficulties.	<b>YES</b>	<b>NO</b>	<b>N/A</b>
Managing my loved one’s swallowing difficulties interferes with my daily routine (e.g., job, school work, household chores).	<b>YES</b>	<b>NO</b>	<b>N/A</b>

Managing my loved one's swallowing difficulties takes away from other things I would prefer to be doing (e.g., leisure activities).	YES	NO	N/A
Because of my loved one's swallowing difficulties, my loved one and I do not participate in meals together as often as we used to.	YES	NO	N/A
Because of my loved one's swallowing difficulties, I do not make plans with others as often as I would like.	YES	NO	N/A
Because of my loved one's swallowing difficulties, my loved one and I cannot go out to eat as much as I would like.	YES	NO	N/A
Because of my loved one's swallowing difficulties, I avoid eating or drinking items that they cannot have.	YES	NO	N/A

**Table 2.** The CARES Questionnaire, Part B – Measures of Subjective Caregiver Stress

*For each of the following statements, please think specifically about your loved one/care recipient's eating or swallowing difficulties **during the past month**. Has the statement been true for **you**?*

**In the past month, has the statement been true for you?**

I do not feel prepared to help manage my loved one's swallowing difficulty (e.g., related to tube feeding, thickened liquids, Heimlich).	YES	NO
Because of my loved one's swallowing difficulties, I feel like it is hard to ensure they receive adequate nutrition.	YES	NO
I feel like my loved one does not do as much as they can to help with their swallowing difficulties.	YES	NO
Because of my loved one's swallowing difficulties, I am scared that they will choke.	YES	NO
Because of my loved one's swallowing difficulties, I feel guilty eating or drinking items that they cannot have.	YES	NO
Because of my loved one's swallowing difficulties, I feel like I don't have enough time to take care of my own physical health.	YES	NO
Because of my loved one's swallowing difficulties, I feel like I don't have enough time for activities that make me feel good.	YES	NO
Because of my loved one's swallowing difficulties, I feel depressed.	YES	NO
Because of my loved one's swallowing difficulties, I feel stressed.	YES	NO
Because of my loved one's swallowing difficulties, I feel anxious.	YES	NO
I feel embarrassed by my loved one's swallowing difficulties when other people are around.	YES	NO
I worry about how my loved one feels about their swallowing difficulties.	YES	NO
Because of my loved one's swallowing difficulties, I feel like the social and togetherness aspects of mealtimes are reduced.	YES	NO
Because of my loved one's swallowing difficulties, I feel isolated from family and friends.	YES	NO

I feel trapped as a result of managing my loved one's swallowing difficulties.	<b>YES</b>	<b>NO</b>
I worry that my loved one's swallowing difficulties will not improve.	<b>YES</b>	<b>NO</b>

**Table 3.** Participant demographic information

<b>Demographic Variable</b>	<b>Mean/Count</b>
Caregiver age (years), Mean $\pm$ SD	49.31 $\pm$ 17.04 (Range 25-77)
Caregiver gender, N (%)	
Female	24 (92.3%)
Male	1 (3.8%)
Not reported	1 (3.8%)
Caregiver relationship to care recipient, N (%)	
Partner/spouse	9 (34.6%)
Child	5 (19.2%)
Parent	11 (42.3%)
Other <sup>a</sup>	1 (3.8%)
Care recipient age, N (%)	
<18	9 (34.6%)
18-24	1 (3.8%)
25-34	1 (3.8%)
35-44	1 (3.8%)
45-54	0 (0.0%)
55-64	4 (15.4%)
65-74	4 (15.4%)
75-84	2 (7.7%)
>84	3 (11.5%)
Not reported <sup>b</sup>	1 (3.8%)
Care recipient has a diagnosis of dysphagia, N (%)	
Yes	23 (88.5%)
No	3 (11.5%)
Caregiver Zarit Burden Score, Mean $\pm$ SD	25.31 $\pm$ 14.33
Caregiver CARES Score, Mean $\pm$ SD	
Part A – Checklist of Behavioral and Functional Changes	4.39 $\pm$ 2.43
Part B – Measures of Subjective Caregiver Stress	10.73 $\pm$ 3.47
Total Score	14.62 $\pm$ 5.13
Care recipient EAT-10 Score (based on proxy report), Mean $\pm$ SD	24.23 $\pm$ 10.72
Care recipient IDDSI-FDS Score (based on proxy report)	
0	4 (15.4%)
1	3 (11.5%)
2	1 (3.8%)
3	3 (11.5%)
4	1 (3.8%)

5	3 (11.5%)
6	7 (26.9%)
7	2 (7.7%)
8	2 (7.7%)

<sup>a</sup> This participant indicated their relationship to be “sister-in-law”.

<sup>b</sup> While no age was reported, this care recipient was determined to be an adult based on additional information provided.

CARES = Caregiver Analysis of Reported Experiences with Swallowing Disorders; EAT-10 = Eating Assessment Tool; IDDSI-FDS = International Dysphagia Diet Standardisation Initiative Functional Diet Scale; *N* = number; *SD* = standard deviation

**Table 4.** Rasch analysis fit indices the CARES Part A.

Item <sup>a</sup>	INFIT (ZSD) <sup>b</sup>	OUTFIT (ZSD)
1. Extra time is required for mealtimes.	1.12 (0.62)	1.06 (0.29)
2. My mealtime- and nutrition-related responsibilities have increased.	0.81 (-1.15)	0.72 (-0.98)
3. The costs associated with nutrition-related needs have increased.	1.08 (0.50)	1.07 (0.33)
4. Other family members disagree with me about how to best manage my loved one’s swallowing difficulties.	1.13 (0.51)	1.06 (0.29)
5. Managing my loved one’s swallowing difficulties interferes with my daily routine.	0.91 (-0.50)	0.83 (-0.55)
6. Managing my loved one’s swallowing difficulties takes away from other things I would prefer to be doing.	1.01 (0.14)	1.10 (0.40)
7. My loved one and I do not participate in meals together as often as we used to.	1.02 (0.19)	0.85 (-0.31)
8. I do not make plans with others as often as I would like.	0.90 (-0.55)	0.80 (-0.67)
9. My loved one and I cannot go out to eat as much as I would like.	1.17 (1.02)	1.11 (0.48)
10. I avoid eating or drinking items that my loved one cannot have.	0.94 (-0.11)	0.83 (-0.19)

<sup>a</sup> Questionnaire items have been condensed. Refer to Table 1 for complete item wording.

<sup>b</sup> ZSD is the INFIT or OUTFIT mean square fit statistic *t* standardized to approximate a theoretical “unit normal,” mean 0 and variance 1, distribution.

**Table 5.** Rasch analysis fit indices the CARES Part B.

Item <sup>a</sup>	INFIT (ZSD) <sup>b</sup>	OUTFIT (ZSD)
1. I do not feel prepared to help manage my loved one's swallowing difficulty.	1.11 (0.64)	1.12 (0.46)

2. I feel like it is hard to ensure they receive adequate nutrition.	0.91 (-0.32)	0.84 (-0.32)
3. I feel like my loved one does not do as much as they can to help with their swallowing difficulties.	1.26 (0.93)	1.04 (0.29)
4. I am scared that my loved one will choke.	1.08 (0.32)	1.25 (0.62)
5. I feel guilty eating or drinking items that they cannot have.	1.49 (2.37)	1.87 (2.36)
6. I feel like I don't have enough time to take care of my own physical health.	0.75 (-1.25)	0.61 (-1.23)
7. I feel like I don't have enough time for activities that make me feel good.	0.83 (-0.41)	0.58 (-0.52)
8. I feel depressed.	1.08 (0.37)	1.08 (0.33)
9. I feel stressed.	0.68 (-0.52)	0.22 (-0.41)
10. I feel anxious.	1.33 (0.86)	2.37 (1.32)
11. I feel embarrassed by my loved one's swallowing difficulties when other people are around.	1.28 (1.18)	1.09 (0.34)
12. I worry about how my loved one feels about their swallowing difficulties.	0.90 (-0.18)	0.74 (-0.21)
13. I feel like the social and togetherness aspects of mealtimes are reduced.	0.97 (0.00)	0.86 (-0.09)
14. I feel isolated from family and friends.	0.65 (-2.06)	0.53 (-1.62)
15. I feel trapped as a result of managing my loved one's swallowing difficulties.	0.59 (-2.26)	0.46 (-1.29)
16. I worry that my loved one's swallowing difficulties will not improve.	0.88 (-0.17)	0.63 (-0.08)

<sup>a</sup>Questionnaire items have been condensed. Refer to Table 2 for complete item wording.

<sup>b</sup>ZSD is the INFIT or OUTFIT mean square fit statistic *t* standardized to approximate a theoretical "unit normal," mean 0 and variance 1, distribution.

**Table 6.** Item mapping of the CARES Part A.

Item	Order of Difficulty <sup>a</sup>
1. Extra time is required for mealtimes.	1
6. Managing my loved one's swallowing difficulties takes away from other things I would prefer to be doing.	1
5. Managing my loved one's swallowing difficulties interferes with my daily routine.	2
8. I do not make plans with others as often as I would like.	2
2. My mealtime- and nutrition-related responsibilities have increased.	3
9. My loved one and I cannot go out to eat as much as I would like.	3
3. The costs associated with nutrition-related needs have increased.	4
7. My loved one and I do not participate in meals together as often as we used to.	5
4. Other family members disagree with me about how to best manage my loved one's swallowing difficulties.	6

10. I avoid eating or drinking items that my loved one cannot have.	6
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<sup>a</sup> 1 = *least difficult* to 6 = *most difficult* for participants to agree with the item and endorse it.

**Table 7.** Item mapping of the CARES Part B.

Item	Order of Difficulty <sup>a</sup>
4. I am scared that my loved one will choke.	1
9. I feel stressed.	1
10. I feel anxious.	2
16. I worry that my loved one's swallowing difficulties will not improve.	2
7. I feel like I don't have enough time for activities that make me feel good.	3
12. I worry about how my loved one feels about their swallowing difficulties.	3
13. I feel like the social and togetherness aspects of mealtimes are reduced.	4
8. I feel depressed.	5
2. I feel like it is hard to ensure they receive adequate nutrition.	6
6. I feel like I don't have enough time to take care of my own physical health.	7
5. I feel guilty eating or drinking items that they cannot have.	8
14. I feel isolated from family and friends.	8
1. I do not feel prepared to help manage my loved one's swallowing difficulty.	9
15. I feel trapped as a result of managing my loved one's swallowing difficulties.	10
11. I feel embarrassed by my loved one's swallowing difficulties when other people are around.	11
3. I feel like my loved one does not do as much as they can to help with their swallowing difficulties.	12

<sup>a</sup> 1 = *least difficult* to 12 = *most difficult* for participants to agree with the item and endorse it.

**Table 8.** Bivariate correlations between the CARES and the EAT-10, IDDSI-FDS, and ZBI.

	<b>EAT-10</b>		<b>IDDSI-FDS</b>		<b>ZBI</b>	
	<i>r<sub>s</sub></i>	<i>p</i> -value	<i>r<sub>s</sub></i>	<i>p</i> -value	<i>r<sub>s</sub></i>	<i>p</i> -value
<b>CARES – Part A</b>	0.634	<.001**	-0.467	.013**	0.628	<.001**
<b>CARES – Part B</b>	0.537	<.001**	-0.160	.217	0.717	<.001**
<b>Total CARES</b>	0.721	<.001**	-0.386	.034	0.798	<.001**

*Note.* \*\* Significant correlation after adjustment for multiple comparisons.

*CARES* = Caregiver Analysis of Reported Experiences with Swallowing Disorders; *EAT-10* = Eating Assessment Tool; *IDDSI-FDS* = International Dysphagia Diet Standardisation Initiative Functional Diet Scale; *ZBI* = Zarit Burden Interview



## References

- Allen, A. P., Curran, E. A., Duggan, Á., Cryan, J. F., Chorcóráin, A. N., Dinan, T. G., Molloy, D. W., Kearney, P. M., & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neuroscience and Biobehavioral Reviews*, *73*, 123-164. <https://doi.org/https://doi.org/10.1016/j.neubiorev.2016.12.006>
- Belafsky, P. C., Mouadeb, D. A., Rees, C. J., Pryor, J. C., Postma, G. N., Allen, J., & Leonard, R. J. (2008). Validity and reliability of the Eating Assessment Tool (EAT-10). *Annals of Otolaryngology, Rhinology and Laryngology*, *117*(12), 919-924.
- Bilotta, C., Bergamaschini, L., Arienti, R., Spreafico, S., & Vergani, C. (2010, May). Caregiver burden as a short-term predictor of weight loss in older outpatients suffering from mild to moderate Alzheimer's disease: a three months follow-up study. *Aging Ment Health*, *14*(4), 481-488. <https://doi.org/10.1080/13607860903586128>
- Carrión, S., Roca, M., Costa, A., Arreola, V., Ortega, O., Palomera, E., Serra-Prat, M., Cabré, M., & Clavé, P. (2017, 2017/08/01/). Nutritional status of older patients with oropharyngeal dysphagia in a chronic versus an acute clinical situation. *Clinical Nutrition*, *36*(4), 1110-1116. <https://doi.org/https://doi.org/10.1016/j.clnu.2016.07.009>
- Dawood, S. (2016). Caregiver burden, quality of life and vulnerability towards psychopathology in caregivers of patients with dementia/Alzheimer's disease. *Journal of the College Physicians Surgeons Pakistan*, *26*(11), 892-895.
- de Wit, J., Bakker, L. A., van Groenestijn, A. C., van den Berg, L. H., Schroder, C. D., Visser- Meily, J. M. A., & Beelen, A. (2018, Jan). Caregiver burden in amyotrophic lateral sclerosis: A systematic review. *Palliative Medicine*, *32*(1), 231-245. <https://doi.org/10.1177/0269216317709965>

- DeVellis, R. F. (2012). *Scale development: Theory and application*. Sage Publications.
- Ekberg, O., Hamdy, S., Woisard, V., Wuttge-Hannig, A., & Ortega, P. (2002, Spring). Social and psychological burden of dysphagia: its impact on diagnosis and treatment. *Dysphagia*, *17*(2), 139-146. <https://doi.org/10.1007/s00455-001-0113-5>
- Epstein-Lubow, G., Gaudiano, B. A., Hinckley, M., Salloway, S., & Miller, I. W. (2010). Evidence for the validity of the American Medical Association's Caregiver Self-Assessment Questionnaire as a screening measure for depression. *Journal of the American Geriatrics Society*, *58*(2), 387-388.
- Ganzer, H., Touger-Decker, R., Byham-Gray, L., Murphy, B. A., & Epstein, J. B. (2015, 2015/07/01/). The eating experience after treatment for head and neck cancer: A review of the literature. *Oral Oncology*, *51*(7), 634-642. <https://doi.org/https://doi.org/10.1016/j.oraloncology.2015.04.014>
- Hébert, R., Bravo, G., & Prévile, M. (2000). Reliability, Validity and Reference Values of the Zarit Burden Interview for Assessing Informal Caregivers of Community-Dwelling Older Persons with Dementia. *Canadian Journal on Aging / La Revue canadienne du vieillissement*, *19*(4), 494-507. <https://doi.org/10.1017/S0714980800012484>
- Howells, S. R., Cornwell, P. L., Ward, E. C., & Kuipers, P. (2020, Apr 24). Living with Dysphagia in the Community: Caregivers "do whatever it takes.". *Dysphagia*. <https://doi.org/10.1007/s00455-020-10117-y>
- Jacob, L., Oh, H., Shin, J. I., Haro, J. M., Vancampfort, D., Stubbs, B., Jackson, S. E., Smith, L., & Koyanagi, A. (2020). Informal Caregiving, Chronic Physical Conditions, and Physical Multimorbidity in 48 Low- and Middle-Income Countries. *The Journals of Gerontology: Series A*. <https://doi.org/10.1093/gerona/glaa017>

Johansson, A. E. M., & Johansson, U. (2009). Relatives' experiences of family members' eating difficulties. *Scandinavian Journal of Occupational Therapy, 16*, 25-32.

<https://doi.org/10.1080/11038120802257195>

Jones, E., Speyer, R., Kertscher, B., Denman, D., Swan, K., & Cordier, R. (2018, Apr). Health-Related Quality of Life and Oropharyngeal Dysphagia: A Systematic Review.

*Dysphagia, 33*(2), 141-172. <https://doi.org/10.1007/s00455-017-9844-9>

Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J., & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health.

*Psychosomatic Medicine, 53*(4).

[https://journals.lww.com/psychosomaticmedicine/Fulltext/1991/07000/Spousal\\_caregivers\\_of\\_dementia\\_victims\\_.1.aspx](https://journals.lww.com/psychosomaticmedicine/Fulltext/1991/07000/Spousal_caregivers_of_dementia_victims_.1.aspx)

Lefton-Greif, M. A., Okelo, S. O., Wright, J. M., Collaco, J. M., McGrath-Morrow, S. A., & Eakin, M. N. (2014, Dec). Impact of children's feeding/swallowing problems: validation of a new caregiver instrument. *Dysphagia, 29*(6), 671-677. <https://doi.org/10.1007/s00455-014-9560-7>

Leow, L. P., Huckabee, M. L., Anderson, T., & Beckert, L. (2010, Sep). The impact of dysphagia on quality of life in ageing and Parkinson's disease as measured by the swallowing quality of life (SWAL-QOL) questionnaire. *Dysphagia, 25*(3), 216-220.

<https://doi.org/10.1007/s00455-009-9245-9>

Linacre, J. M. (2010). *WINSTEPS Rasch measurement computer program*. In (Version 3.69.1.8) Winsteps.com.

Linacre, J. M. (2012). What do infit and outfit, mean-square and standardized mean? *Rasch Measurement Transactions, 16*(2), 878.

- Liu, S., Li, C., Shi, Z., Wang, X., Zhou, Y., Liu, S., Liu, J., Yu, T., & Ji, Y. (2017). Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *Journal of Clinical Nursing*, 26(9-10), 1291-1300.
- Longacre, M. L., Galloway, T. J., Parvanta, C. F., & Fang, C. Y. (2015). Medical Communication-related Informational Need and Resource Preferences Among Family Caregivers for Head and Neck Cancer Patients. *Journal of Cancer Education*, 30(4), 786-791. <https://doi.org/10.1007/s13187-015-0814-3>
- Martino, R., Beaton, D., & Diamant, N. E. (2010). Perceptions of Psychological Issues Related to Dysphagia Differ in Acute and Chronic Patients. *Dysphagia*, 25, 26-34. <https://doi.org/10.1007/s00455-009-9225-0>
- Maxim, L. D., Niebo, R., & Utell, M. J. (2014). Screening tests: A review with examples. *Inhalation Toxicology*, 26(13), 811-828. <https://doi.org/10.3109/08958378.2014.955932>
- McPherson, C. J., & Addington-Hall, J. M. (2003). Judging the quality of care at the end of life: Can proxies provide reliable information? *Social Science & Medicine*, 56(1), 95–109.
- Miller, N., Noble, E., Jones, D., & Burn, D. (2006, Nov). Hard to swallow: dysphagia in Parkinson's disease. *Age and Ageing*, 35(6), 614-618. <https://doi.org/10.1093/ageing/af1105>
- Moloney, J., & Walshe, M. (2018, 2018/06/19). “I had no idea what a complicated business eating is...”: a qualitative study of the impact of dysphagia during stroke recovery. *Disability and Rehabilitation*, 40(13), 1524-1531. <https://doi.org/10.1080/09638288.2017.1300948>
- Namasivayam-MacDonald, A. M., & Shune, S. (2020). The influence of swallowing impairments as an independent risk factor for burden among caregivers of aging parents: A cross-sectional study. *Geriatric Nursing*, 41(2), 81-88. <https://doi.org/10.1016/j.gerinurse.2019.06.008>

- Namasivayam-MacDonald, A. M., & Shune, S. E. (2018). The burden of dysphagia on family caregivers of the elderly: A systematic review. *Geriatrics*, 3(2), 30.  
<https://doi.org/10.3390/geriatrics3020030>
- Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, 29, 798-803.
- Nund, R. L., Scarinci, N. A., Cartmill, B., Ward, E. C., Kuipers, P., & Porceddu, S. V. (2016). Third-party disability in carers of people with dysphagia following non-surgical management for head and neck cancer. *Disability and Rehabilitation*, 38(5), 462-471.  
<https://doi.org/10.3109/09638288.2015.1046563>
- Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014a). Carers' experiences of dysphagia in people treated for head and neck cancer: A qualitative study. *Dysphagia*, 29, 450-458. <https://doi.org/10.1007/s00455-014-9527-8>
- Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014b, 2014/06/01). The lived experience of dysphagia following non-surgical treatment for head and neck cancer. *International Journal of Speech-Language Pathology*, 16(3), 282-289. <https://doi.org/10.3109/17549507.2013.861869>
- Oczkowski, C., & O'Donnell, M. (2010). Reliability of proxy respondents for patients with stroke: A systematic review. *Journal of Stroke and Cerebrovascular Diseases*, 19(5), 410-416. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2009.08.002>
- Patterson, J. M., Rapley, T., Carding, P. N., Wilson, J. A., & McColl, E. (2013). Head and neck cancer and dysphagia; caring for carers. *Psycho-Oncology*, 22, 1815-1820.  
<https://doi.org/10.1002/pon.3226>
- Penner, J. L., McClement, S., Lobchuk, M., & Daeninck, P. (2012). Family members' experiences caring for patients with advanced head and neck cancer receiving tube

- feeding: A descriptive phenomenological study. *Journal of Pain and Symptom Management*, 44(4), 563-571.
- Robinson, B. C. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology*, 38(3), 344-348.
- Rolland, J. S. (1994). *Families, Illness, & Disability*. BasicBooks.
- Rolland, J. S. (2017). Neurocognitive Impairment: Addressing Couple and Family Challenges. *Family Process*, 56(4), 799-818. <https://doi.org/10.1111/famp.12316>
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309-319.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association*, 282(23), 2215-2219.
- Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: The caregiver health effects study: An ancillary study of the cardiovascular health study. *Annals of Behavioral Medicine*, 19(2), 110-116.  
<https://doi.org/10.1007/BF02883327>
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates, and Causes. *The Gerontologist*, 35(6), 771-791. <https://doi.org/10.1093/geront/35.6.771>
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, 44(sup3), 105-113.
- Seshadri, S., Sellers, C. R., & Kearney, M. H. (2018, Jul 13). Balancing Eating With Breathing: Community-Dwelling Older Adults' Experiences of Dysphagia and Texture-Modified Diets. *Gerontologist*, 58(4), 749-758. <https://doi.org/10.1093/geront/gnw203>

- Shune, S., & Namasivayam-MacDonald, A. M. (2020). Swallowing impairments increase emotional burden in spousal caregivers of older adults. *Journal of Applied Gerontology*, *39*(2), 172-180. <https://doi.org/10.1177/0733464818821787>
- Shune, S., & Namasivayam-MacDonald, A. M. (in press). Caregiver burden in dysphagia: Moving beyond the physiological impairment. *Perspectives on Swallowing and Swallowing Disorders*.
- Smith, E., & Smith, R. M. (2004). *Introduction to Rasch measurement*. JAM Press.
- Stagg, B., & Lerner, A. J. (2015). Zarit Burden Interview: Pragmatic study in a dedicated cognitive function clinic. *Progress in Neurology and Psychiatry*, *19*(4), 23-27.
- Stall, N. M., Kim, S. J., Hardacre, K. A., Shah, P. S., Straus, S. E., Bronskill, S. E., Lix, L. M., Bell, C. M., & Rochon, P. A. (2019, Dec 10). Association of Informal Caregiver Distress with Health Outcomes of Community-Dwelling Dementia Care Recipients: A Systematic Review. *Journal of the American Geriatrics Society*, *67*(3), 609-617. <https://doi.org/10.1111/jgs.15690>
- Steele, C. M., Namasivayam-MacDonald, A. M., Guida, B. T., Cichero, J. A., Duivesteyn, J., Hanson, B., Lam, P., & Riquelme, L. F. (2018, May). Creation and Initial Validation of the International Dysphagia Diet Standardisation Initiative Functional Diet Scale. *Archives of Physical Medicine and Rehabilitation*, *99*(5), 934-944. <https://doi.org/10.1016/j.apmr.2018.01.012>
- Suiter, D. M., Daniels, S. K., Barkmeier-Kraemer, J. M., & Silverman, A. H. (2020). Swallowing Screening: Purposefully Different From an Assessment Sensitivity and Specificity Related to Clinical Yield, Interprofessional Roles, and Patient Selection. *American Journal of Speech-Language Pathology*, *29*(2S), 979-991. [https://doi.org/10.1044/2020\\_ajslp-19-00140](https://doi.org/10.1044/2020_ajslp-19-00140)

- Thornton, M., & Travis, S. S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *Journal of Gerontology: Social Sciences, 58B*(2), S127-S132.
- Torti, F. M. J., Gwyther, L. P., Reed, S. D., Friedman, J. Y., & Schulman, K. A. (2004). A multinational review of recent trends and reports in dementia caregiver burden. *Alzheimer Disease and Associated Disorders, 18*(2), 99-109.  
<https://doi.org/10.1097/01.wad.0000126902.37908.b2>
- Tsujimura, T., & Inoue, M. (2020). Evaluation of the association between orofacial pain and dysphagia. *Journal of Oral Science, 62*(2), 156-159. <https://doi.org/10.2334/josnusd.19-0408>
- Verdonschot, R., Baijens, L. W. J., Vanbelle, S., van de Kolk, I., Kremer, B., & Leue, C. (2017, Jun). Affective symptoms in patients with oropharyngeal dysphagia: A systematic review. *Journal of Psychosomatic Research, 97*, 102-110.  
<https://doi.org/10.1016/j.jpsychores.2017.04.006>
- Wilson, J. M. G., Jungner, G., & World Health, O. (1968). Principles and practice of screening for disease.
- Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine, 176*(3), 372-379.
- Wright, B. D., & Linacre, J. M. (1994). Reasonable mean square fit values. *Rasch Measurement Transactions, 8*, 370.
- Yi, Y. G., Oh, B. M., Seo, H. G., Shin, H. I., & Bang, M. S. (2019, Apr). Dysphagia-Related Quality of Life in Adults with Cerebral Palsy on Full Oral Diet Without Enteral Nutrition. *Dysphagia, 34*(2), 201-209. <https://doi.org/10.1007/s00455-018-09972-7>
- Yoshimura, Y., Wakabayashi, H., Bise, T., & Tanoue, M. (2018, Dec). Prevalence of sarcopenia and its association with activities of daily living and dysphagia in convalescent



rehabilitation ward inpatients. *Clinical Nutrition*, 37(6 Pt A), 2022-2028.

<https://doi.org/10.1016/j.clnu.2017.09.009>

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly:

Correlates of feelings of burden. *The Gerontologist*, 20(6), 649-655.

<https://doi.org/10.1093/geront/20.6.649>

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as

caregivers: A longitudinal study. *The Gerontologist*, 26(3), 260-266.