

This is the Accepted Manuscript of an article published by the American Speech-Language Hearing Association (ASHA) in the Journal of Speech-Language Pathology © 2021. The manuscript is reprinted here with permission from ASHA and is further available online: https://pubs.asha.org/doi/10.1044/2021_AJSLP-20-00250

Contributors to Post-stroke Dysphagia-related Caregiver Burden

Cameron Davis¹, Ashwini M. Namasivayam-MacDonald², and Samantha E. Shune¹

1. Communication Disorders and Sciences, University of Oregon, Eugene, Oregon
2. School of Rehabilitation Science, McMaster University, Hamilton, Canada

Corresponding author:
Samantha E. Shune, PhD, CCC-SLP
249 HEDCO Education Building
5284 University of Oregon
Eugene, OR 97403
Email: sshune@uoregon.edu
Phone: (541) 346-7494

Conflicts of Interest: There are no conflicts of interest to report.

Funding: This work was supported by an AARC (Advancing Academic-Research Careers) Award from the American Speech-Language-Hearing Association (to S. Shune).

Abstract

Purpose: Caregiver burden negatively impacts both stroke survivor and caregiver well-being. Thus, it is important to better understand the individual- and dyadic-level variables that may contribute to dysphagia-related caregiver burden. The aim of this preliminary study was to identify survivor-, caregiver-, and dyadic-specific factors associated with burden in couples experiencing post-stroke dysphagia.

Methods: Twenty-eight stroke survivors (“care recipients”) with dysphagia and their spouses (“caregivers”) participated. Care recipients and caregivers completed a survey from which scores for the following variables were derived: dysphagia-related caregiver burden, survivor- and spouse-perceived impact of dysphagia on mealtimes (social, mealtime logistics), dyadic congruence on perceived impact, IDDSI Functional Diet Scale (IDDSI-FDS), Swallowing-Related Quality of Life (SWAL-QOL), and Stroke Impact Scale (cognitive, emotional, physical, social domains). Spearman’s Rho and point-biserial correlation coefficients were calculated to determine the factors related to caregiver burden.

Results: Increased burden was significantly associated with greater care recipient- and spouse-perceived impact of dysphagia on mealtime logistics; however, burden was not associated with measures of dyadic congruence of perceived impact. Notably, increased burden was also associated with increased diet restrictiveness and decreased swallow-specific quality of life.

Dysphagia-related caregiver burden was not associated with measures of stroke impact/severity across any domain.

Conclusions: Factors related to dysphagia-related caregiver burden are multifactorial and include both care recipient (e.g., IDDSI-FDS, SWAL-QOL, perceived impact of dysphagia on mealtime logistics) and caregiver (e.g., perceived impact of dysphagia on mealtime logistics) variables.

The results of this preliminary investigation support the need to incorporate aspects of counseling and family-centered care into our management practices, a growing area of interest for speech-language pathologists.

Keywords: caregiver burden; deglutition; dysphagia; stroke

Introduction

Up to 80% of stroke survivors experience dysphagia, with dysphagia persisting in 50% of these survivors for at least six months (Mann et al., 1999; Takizawa et al., 2016). As stroke is the leading cause of long-term disability in the United States, the annual nationwide incidence of stroke-related dysphagia is in the tens of millions (Mozaffarian et al., 2015). Dysphagia is likely one strong contributor to the biopsychosocial impacts of stroke and has been linked to lower quality of life and increased morbidities and mortality among survivors (e.g., Arnold et al., 2016; Foley et al., 2009; Klinke et al., 2013; Martino et al., 2005; Smithard et al., 1996; Smithard et al., 2007).

Crucially, the influence of stroke and dysphagia extend well beyond the individual survivor. Informal caregiving has become a primary source of care provision for older adults, with nearly 44 million Americans serving as caregivers for these individuals (Chari et al., 2015). Unfortunately, the shift in role from relative to primary caregiver and the increased demands placed on these individuals can lead to significant caregiver burden. Caregiver burden is the additional emotional, financial, or physical stress a person experiences as a result of caring for another person (Adelman et al., 2014; George & Gwyther, 1986). The consequences of a high level of burden are often substantial and can include an increased risk of mental illness, such as anxiety and depression, physical multimorbidities, feelings of frustration or resentment, and decreased physical health, immunity, self-efficacy, and subjective well-being (Jacob et al., 2020; Kiecolt-Glaser et al., 1991; LaManna et al., 2020; McCarthy & Lyons, 2015; Pinquart & Sorensen, 2003; Schulz et al., 1997). Increased emotional strain and poorer caregiver mental health have been found to be independent risk factors for caregiver mortality (Lwi et al., 2017; Schulz & Beach, 1999).

Caregiver burden can also negatively impact the care recipient's health and well-being (Isaac et al., 2011; Torti et al., 2004; Wolff et al., 2016). The addition of emotional, physical, and/or financial burden can lead to decreased caregiver health, which can negatively impact their ability to provide care. As such, the consequences of high caregiver burden are often cyclical; high levels of burden can lead to poorer caregiver health outcomes, which in turn can impact the level of care provided to the care recipient, resulting in poorer outcomes for care recipient health as well (Shune & Namasivayam-MacDonald, 2020a). This model suggests the interdependence of patient and caregiver health outcomes, highlighting the clinical importance of considering both members of the caregiving dyad. Previous research has explored this interdependence among stroke survivors and their caregivers. For example, Pucciarelli et al. (2019) conducted a longitudinal study of quality of life trajectories in stroke survivors. The authors found that a stroke survivor's quality of life trajectory mirrored their informal caregivers' levels of burden, anxiety, and depression during the first year after the stroke. Thus, at issue is how to best support the needs of both patients and their caregivers in order to maximize health-related and quality of life outcomes. Yet, it is necessary to first recognize the factors that increase this caregiver burden and better understand how these factors contribute to burden.

Interestingly, previous work has demonstrated that dysphagia is one independent predictor of general caregiver burden, even when controlling for established burden risk factors such as health status and age. Spouses caring for an aging partner with dysphagia were found to be 2.06 times more likely to experience emotional burden than spousal caregivers whose partner did not have dysphagia, with 70% of the caregivers of individuals with dysphagia who reported emotional burden rating that burden as moderate to severe (Shune & Namasivayam-MacDonald, 2020b). Similarly, adults caring for an aging parent with dysphagia were found to be 1.61 times

more likely to experience emotional burden and 1.71 times more likely to experience physical burden than adults caring for an aging parent without dysphagia (Namasivayam-MacDonald & Shune, 2020). Thus, dysphagia appears to be one important health factor to consider not only for care recipient health and well-being, but also as related to caregiver burden. Given the high prevalence of post-stroke dysphagia and the negative consequences of dysphagia on stroke survivors, including increased care needs, it is likely that post-stroke dysphagia also contributes to the burden experienced by their caregivers.

There are a number of potential mechanisms through which dysphagia impacts burden, which have previously been framed within the World Health Organization's (WHO) conceptualization of "third-party disability," or disability in caregivers/family members that results from their loved one's chronic illness (WHO, 2001). Decreased support and social involvement outside of the home, increased responsibilities, and resulting anxiety, sadness, guilt, and isolation have previously been described as components of this third-party disability among caregivers of a wide range of individuals with dysphagia, suggesting components of dysphagia-specific burden (e.g., Johansson & Johansson, 2009; Nund et al., 2016; Nund et al., 2014b; Patterson et al., 2013). Other research has suggested that dysphagia severity, as measured through the use of feeding tubes and worsening feeding behaviors, may also contribute to increased general caregiver burden (Bentur et al., 2015; Namasivayam-MacDonald & Shune, 2018; Riviere et al, 2002). Yet, much of this research has been conducted with caregivers of head and neck cancer survivors and individuals with dementia. Predictors of general caregiver burden following stroke have also reflected both survivor and caregiver characteristics, including increased functional limitations or post-stroke disability, such as physical deficits and cognitive

dysfunction, increased time spent caregiving, and survivor and caregiver mental health disturbances (e.g., Byun & Evans, 2014; Choi-Kwon et al., 2005; Rigby et al., 2009).

This previous research has also only primarily explored individual-level factors, such as those related to the care recipient and those related to the caregiver. Given the interdependence between care recipient and caregiver health and well-being, dyadic-level factors may be equally as, or more valuable, to consider. The Dyadic Illness Management Theory (Lyons & Lee, 2018) conceptualizes couple dyads as interdependent teams whose main goal is to optimize the health of both partners. One key component of this theory is dyadic appraisal, or perception, of the illness' impact. Lyons and Lee suggest that congruence, or agreement, in dyadic appraisal is more important than each individuals' separate appraisal for overall dyadic health. It has been found that increased congruence in dyadic appraisal, along with increased dyadic management behaviors, are protective factors for positive outcomes in the presence of chronic illness, whereas increased incongruence in dyadic appraisal is a risk factor for negative outcomes.

In order to optimize management approaches and outcomes, it is important to better understand the individual- and dyadic-level variables that may contribute to post-stroke caregiver burden. The aim of this preliminary study was to identify specific survivor, caregiver, and dyadic factors associated with caregiver burden in couples experiencing post-stroke dysphagia. Specifically, we aimed to delineate the relationships between (a) dysphagia-related caregiver burden and (b) care recipient-specific disease characteristics (stroke, dysphagia) as well as individual and dyadic appraisal of dysphagia's impact on mealtimes. Based on the previous literature, it was hypothesized that increased levels of diet restrictiveness, worse perceived impact of dysphagia, and incongruence between spouse and stroke survivor appraisal of dysphagia's impact on mealtimes would be associated with increased levels of caregiver burden

(Shune & Namasivayam-MacDonald, 2020b; Poort et al., 2016). Supporting the presence of aspects of burden specific to dysphagia, it was also hypothesized that stroke severity would not be associated with dysphagia-related caregiver burden.

Methods

Participants

In order to best capture a variety of experiences, inclusion criteria for participation were broad. Survivor participants (the “care recipient”) were at least 18 years old, had their most recent stroke at least 3 months prior to participating, and were living with a spouse who was providing some degree of caregiving for the survivor. All survivors needed to be medically stable, be experiencing some degree of eating or swallowing difficulties, have no other comorbidities that would significantly impact their swallowing status, have not had a diagnosis of dysphagia prior to the most recent stroke, and be currently participating in mealtimes by consuming at least a portion of their nutrition orally. Partner participants (the “caregiver”) were also at least 18 years old and were the spouses of the survivors. Information about study participation was disseminated via online message boards and listservs for stroke survivors and speech-language pathologists as well as through flyers posted in rehabilitation facilities and outpatient clinics. Given that this was a survey study with minimal risks associated, an information statement was presented to all participants prior to completion and consent was assumed through completion of the survey. Participants received financial compensation for completing the surveys. The Institutional Review Board at the participating universities approved all study procedures.

Data Collection and Outcome Measures

All care recipients and spousal caregivers completed a survey containing a participant demographic information questionnaire, a mealtime impact questionnaire (see sample spousal questionnaire in Appendix A), and two questions related to foods and liquids consumed to derive an International Dysphagia Diet Standardisation Initiative Functional Diet Scale (IDDSI-FDS) score (Steele et al., 2018) as a measure of diet restrictiveness. The mealtime impact questionnaire was developed specifically for the purposes of the current study to capture the perceived impact of dysphagia on both the social aspects of mealtimes and mealtime logistics. The same questionnaire was administered to both members of the dyad. Two speech-language pathologists (one clinical researcher with expertise in dysphagia and one hospital-based board-certified specialist in dysphagia) developed the questionnaire. An initial list of relevant domains based on the ICF framework was generated based on the head and neck cancer literature (Nund et al., 2014a, 2016). Excluded from this list were domains addressing problems unique to the head and neck cancer population (e.g., loss of saliva/salivary glands). Additional questions were added based on salient components of the Family Systems-Illness Model (Rolland, 1994) that did not appear to be addressed elsewhere. The two speech-language pathologists along with three survivor-spouse dyads reviewed the questionnaire's face and content validity. Feedback regarding content, redundancy, organization, and clarity lead to the revisions incorporated into the final version of the questionnaire. The final questionnaire used a 6-point Likert scale for responses, although open-ended questions were also included in the overall survey materials to allow participants to provide additional details and/or describe topics not already addressed.

In addition, the care recipients also completed two additional survey sections: the Swallowing-related Quality of Life scale (SWAL-QOL; McHorney et al., 2002) and the Stroke

Impact Scale (SIS; Duncan et al., 1999), both of which are validated and reliable measures to quantify self-perceived impact of swallowing and stroke, respectively, on daily functioning and quality of life. A summary of data measurement tools is presented in Table 1.

Table 1. Summary of data measurement tools and outcome variables

Measurement Tool	Data Collected
Demographic Questionnaire	Background information ^{a,b}
Mealtime Impact Questionnaire	Dysphagia-related caregiver burden ^b Impact of dysphagia on social aspects of mealtime ^{a,b} Impact of dysphagia on mealtime logistics ^{a,b}
Multiple Choice Questions on Typical Foods and Beverages Consumed	Diet restrictiveness via the International Dysphagia Diet Standardisation Initiative Functional Diet Scale (IDDSI-FDS) ^a
Swallowing-related Quality of Life (SWAL-QOL) Scale	Impact of swallowing on quality of life and daily functioning ^a
Stroke Impact Scale (SIS)	Impact of stroke on quality of life and daily functioning ^a

^a Data collected from the care recipient (stroke survivor)

^b Data collected from the caregiver (spouse)

Data Analysis

Descriptive statistics (e.g., median, mean, standard deviation) were used to analyze demographic information. The IDDSI-FDS, SWAL-QOL, and SIS scores were calculated according to standard procedures. IDDSI-FDS scores may range from 0 to 8, with a score of 8 indicating that the individual has no diet modifications and a score of 0 indicating that the individual eats and drinks nothing by mouth. IDDSI-FDS scores in the current study were dichotomized into “modified diet” (IDDSI-FDS scores 1-7) and “unmodified diet” (IDDSI-FDS score 8) for all analyses. Total SWAL-QOL scores reflect a composite of the scaled scores across each included domain (burden, eating desire, eating duration, food selection, communication, fear, mental health, social), expressed as a percentage of the maximum possible domain score, with scores ranging from 0 (worst) to 100 (best). Summative SIS scores are generated across four domains, expressed as a percentage of the maximum possible raw score: physical, cognitive, emotional, and social. Each domain score can range from 0 (worst) to 100 (best).

Data from the mealtime impact questionnaire were used to derive a caregiver burden score, reflecting the caregiving spouse’s level of dysphagia-related burden, as well as estimates of survivor and spouse appraisal of the impact of dysphagia on aspects of the mealtime (social, mealtime logistics). Items for each measure were scored from 0 to 6 (0 = N/A; 1-6 on Likert scale) and summed to yield a total score, with a higher score indicating increased burden and/or perceived impact. Social and mealtime logistics scores were calculated separately for survivors and spouses. Additionally, continuous congruence scores were calculated to examine dyadic appraisal by subtracting the survivor’s score from the spouse’s score. Given the interest in overall congruence/incongruence rather than direction, the absolute value of the continuous congruence scores was calculated.

Validity of the developed questionnaires was assessed using Cronbach's alphas (internal consistency). An alpha coefficient of .70 or greater is generally considered to be acceptable (DeVellis, 2012). To examine congruence between survivor and spouse ratings of dysphagia's impacts, intraclass correlation coefficients (ICC) were calculated. The strength of congruence was labeled as follows: ≤ 0.40 poor to fair agreement, 0.41-0.60 moderate agreement, 0.61-0.80 good agreement, and 0.81-1.00 excellent agreement (Landis & Koch, 1977). Paired *t*-tests were used to examine potential group differences in perceived impact between the survivors and their caregivers. To target the primary study aims, Spearman's Rho and point-biserial correlation coefficients were calculated in order to examine the potential relationships between caregiver burden and perceived functional disability (SWAL-QOL, SIS), diet restrictiveness (IDDSI-FDS), and appraisal of dysphagia's impact on mealtimes (individual appraisal, dyadic congruence). To adjust for multiple comparisons, the Holm's step-down procedure was applied to this analysis. All statistical analyses were completed using SPSS (Version 26, IBM Corporation, Armonk, NY).

Results

Participants

A total of 61 surveys were completed and validated. Five surveys were excluded for the following reasons: only one member of the dyad participated; the dyad had a non-spousal relationship; and the survivor was on complete enteral feeding. Thus, a total of 56 surveys (91.8%) from 28 care recipient-spousal caregiver dyads were included for data analysis.

Table 2. Stroke survivor participant demographic information ($N = 28$)

Characteristic	
Gender (female), n (%)	8 (28.5%)
Age (years), mean \pm SD	60.0 \pm 12.5 (range 33–88)
Race/Ethnicity, n (%)	
White	20 (71.4%)
Hispanic/Latino	1 (3.6%)
Black	7 (25.0%)
Work Status, n (%)	
Full-time	4 (14.3%)
Part-time	4 (14.3%)
Unemployed	4 (14.3%)
Retired	16 (57.1%)
Education, n (%)	
High school	6 (21.4%)
Certificate beyond high school	6 (21.4%)
Some college	1 (3.6%)
Bachelor's degree	8 (28.6%)
Master's degree or higher	5 (17.9%)
Time Since Stroke (months), median (IQR)	12.5 (4.5–41.5) (range 3–550)
Stroke Type, n (%)	
Ischemic	10 (35.7%)
Hemorrhagic	5 (17.9%)
Unknown	11 (39.3%)
Stroke Localization, n (%)	
Right	5 (17.9%)
Left	7 (25.0%)
Other/Unknown	16 (57.1%)
Number of Strokes, n (%)	
One	16 (57.1%)
Two	8 (28.6%)
Three or more	2 (7.1%)
No Response	2 (7.1%)
Reported Swallowing Difficulties, n (%)	
Yes	21 (75.0%)
No	5 (17.9%)
No Response	2 (7.1%)
Receiving Speech Therapy for Swallowing	
Yes	4 (14.3%)
No	22 (78.6%)
No Response	2 (7.1%)
SIS Score, mean \pm SD	
Physical	64.9 \pm 20.7
Cognitive	77.6 \pm 18.7

Emotional	64.4 ± 18.1
Social	61.6 ± 24.5
SWAL-QOL Score, mean ± SD	61.6 ± 21.6
IDDSI-FDS Score, <i>n</i> (%)	
0	0 (0%)
1	1 (3.6%)
2	1 (3.6%)
3	1 (3.6%)
4	1 (3.6%)
5	1 (3.6%)
6	2 (7.1%)
7	8 (28.6%)
8	13 (46.4%)

IDDSI-FDS = International Dysphagia Diet Standardisation Initiative – Functional Diet Scale; *IQR* = interquartile range *N* = number; *SD* = standard deviation; *SIS* = Stroke Impact Scale; *SWAL-QOL* = Swallowing-Related Quality of Life scale

Table 3. Spouse participant demographic information (*N* = 28)

Characteristic	
Gender (female), <i>n</i> (%)	20 (71.4%)
Age (years), mean ± SD	57.1 ± 12.0 (range 32-86)
Race/Ethnicity, <i>n</i> (%)	
White	21 (75.0%)
Black	6 (21.4%)
Decline to answer	1 (3.6%)
Work Status, <i>n</i> (%)	
Full-time	10 (35.7%)
Part-time	10 (35.7%)
Unemployed	1 (3.6%)
Retired	6 (21.4%)
Other	1 (3.6%)
Education, <i>n</i> (%)	
High school	6 (21.4%)
Certificate beyond high school	6 (21.4%)
Some college	2 (7.1%)
Bachelor's degree	12 (42.9%)
Master's degree or higher	2 (7.1%)
Burden ^a mean ± SD	55.1 ± 14.7

^a Burden scores were determined based on the study-specific measures with total possible scores ranging from 0-120.

N = number; *SD* = standard deviation

Tables 2 and 3 present the demographic information for the survivors and spouses, respectively. The participants encompassed a wide range of ages (survivors: $M = 60.0$ years, $SD = 12.5$, range 33-88; spouses: $M = 57.1$, $SD = 12.0$, range 32-86), time since stroke (Median = 12.5 months, IQR 4.5-41.5 months, range 3-550 months), and educational levels (approximately 50% with a college degree or higher). The majority of survivors were retired (57.1%) while the majority of spouses were working at least part-time (71.4%). Care recipients reported a range of concomitant health problems in addition to having had a stroke, including hypertension (46.4%), heartburn (25.0%), bad eyesight (21.4%), back and/or hip pain (17.9%), depression and/or anxiety (17.9%), diabetes (14.3%), breathing difficulties (10.7%), obesity (10.7%), and arthritis and/or osteoporosis (7.1%). Only 28.6% of care recipients reported no concomitant health problems. Survivors' scores for the SIS domains, SWAL-QOL, and IDDSI-FDS can also be found in Table 2. In general, survivors were least impacted by their strokes in the cognitive domain and experienced moderate impairments across the physical, emotional, and social domains. SWAL-QOL scores for these participants ranged from 0 to 100, with an average score of 61.6 ($SD = 21.6$). IDDSI-FDS scores for this sample ranged from 1 to 8. Over half of the care recipients were on a modified diet (53.6%). Out of those participants with diet modifications, more than half (53.3%) scored a 7, indicating only a slight modification to the diet. All possible scores between 1 and 8 were represented in the sample.

One survivor participant did not complete all of the mealtime logistics questions; their data were excluded from analysis for this measure only.

Reliability of Study Specific Measures

Based on the calculations of internal consistency, the final caregiver burden scale included 20 items, with total possible scores ranging from 0-120 ($\alpha = .838$). The mealtime

logistics scale included 5 items, with total possible scores ranging from 0-30 ($\alpha = .730$ for survivors, $\alpha = .739$ for spouses) and the mealtime social scale included 6 items, with total possible scores ranging from 0-36 ($\alpha = .781$ for survivors, $\alpha = .732$ for spouses).

Dyadic Congruence

There was moderate to good congruence between survivors' and spouses' perceptions of dysphagia's impact on mealtime logistics (ICC = .591; 95% CI: 0.112-0.813) and the social aspects of mealtimes (ICC = .722; 95% CI: 0.404-0.871). Neither survivors nor spouses consistently reported a greater impact of dysphagia on mealtimes (mealtime logistics: $t(1,26) = 0.865, p = .395$; social $t(1,27) = 1.013, p = .320$). Overall, 15 out of 28 (53.6%) spouses rated the impact of dysphagia on mealtime logistics as less severe than survivors did, 9 (32.1%) spouses rated the impact as more severe, and 3 (10.7%) survivor-spouse dyads had the same scores. Similarly, 13 out of 28 (46.4%) spouses rated the impact of dysphagia on the social aspects of mealtimes less severe than survivors did, 12 (42.9%) spouses rated the impact as more severe, and 3 (10.7%) dyads had the same scores.

Relationship Between Burden, Appraisal, and Disease Impact

Table 4 presents the results of the correlation analyses between (a) dysphagia-related caregiver burden and (b) measures of perceived functional disability (SWAL-QOL, SIS), diet restrictiveness (IDDSI-FDS), and appraisal of dysphagia's impact on mealtimes (individual and dyadic congruence). Increased burden was significantly associated with greater survivor- and spouse-perceived impact of dysphagia on mealtime logistics ($r_s = .547, p = .002$ and $r_s = .758, p < .001$, respectively; see Figures 1 and 2). However, burden was not associated with measures of dyadic appraisal congruence ($r_s = -.241, p = .113$; $r_s = -.259, p = .092$ for mealtime logistics and social impact, respectively). There was a similar trend for an association between caregiver

burden and perceived impact of dysphagia on the social aspects of mealtimes, but this did not reach significance when adjusting for multiple comparisons ($r_s = .401, p = .017$; $r_s = .389, p = .021$, for care recipient and caregiver, respectively). Notably, increased burden was also associated with increased diet restrictiveness ($r_{pb} = -.647, p < .001$; see Figure 3) and decreased swallow-specific quality of life ($r_s = -.566, p = .001$; see Figure 4). Dysphagia-related caregiver burden was not associated with measures of stroke impact/severity across any domain ($p > .05$ for all; see Table 3). Post-hoc analyses revealed that both care recipient- and caregiver-perceived impact of dysphagia on mealtime logistics were associated with IDDSI-FDS scores ($r_{pb} = -.563, p = .002$; $r_{pb} = -.698, p < .001$ for care recipient and caregiver, respectively).

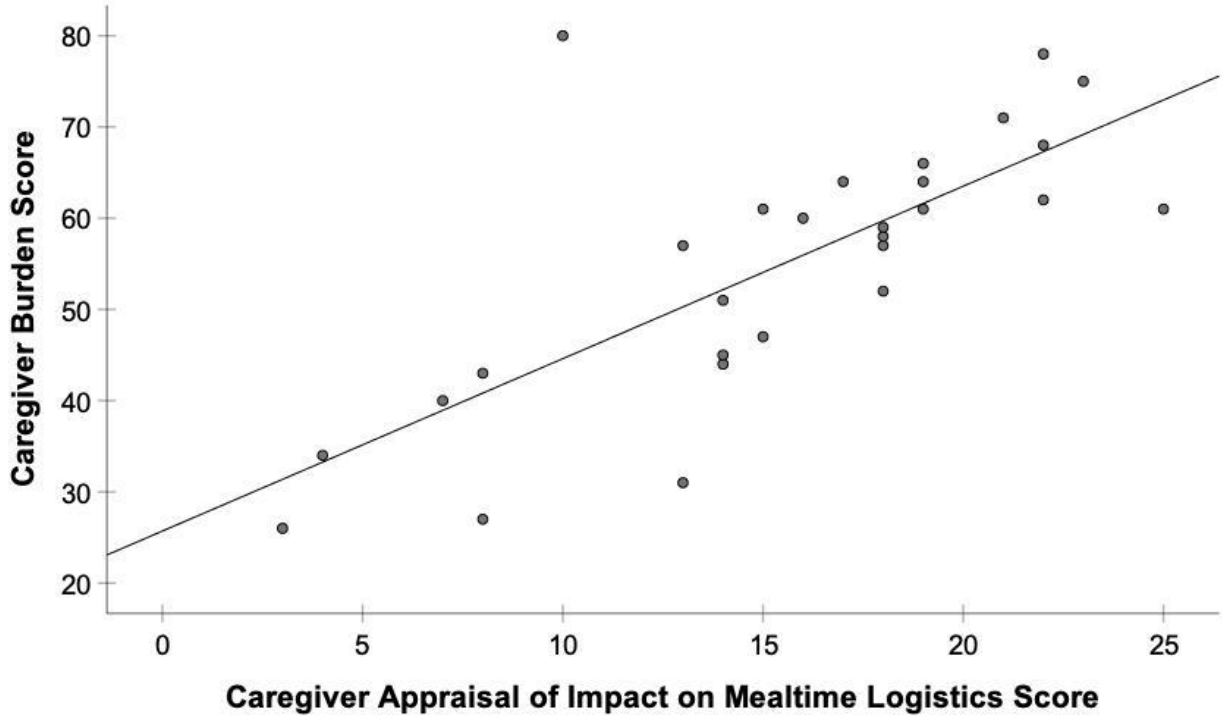
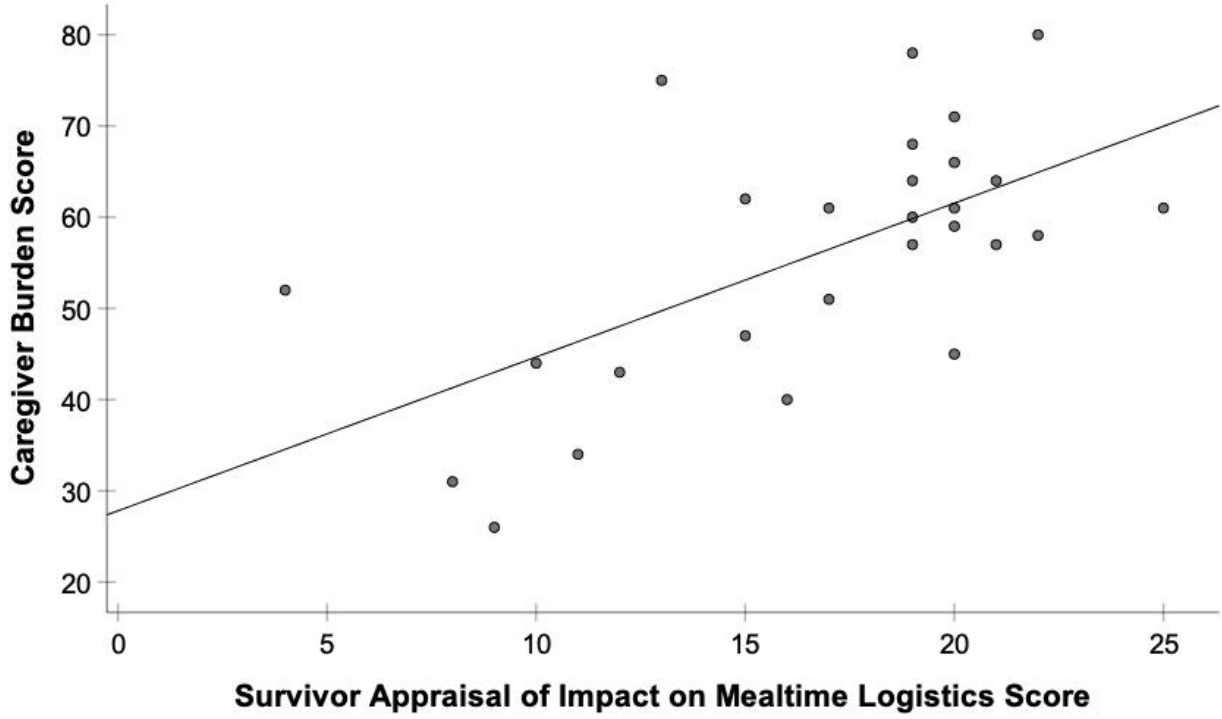
Table 4. Correlations between (a) dysphagia-related spousal burden and (b) appraisal, congruence, and survivor-specific disease characteristics.

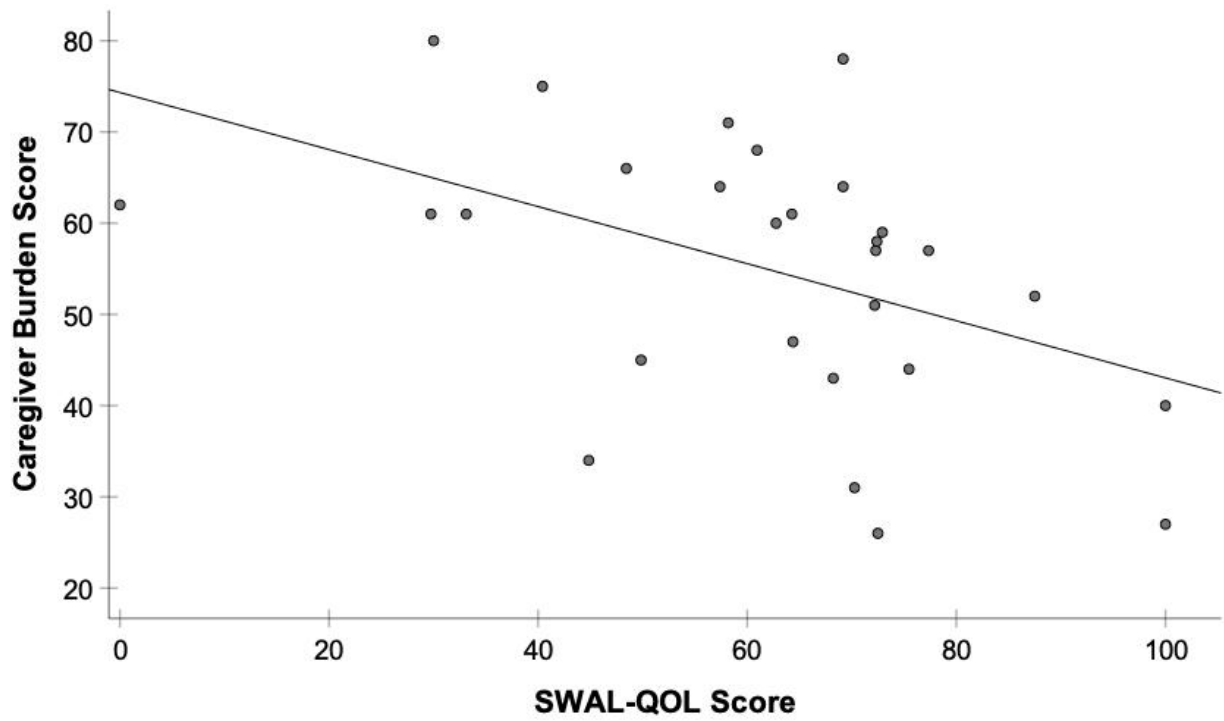
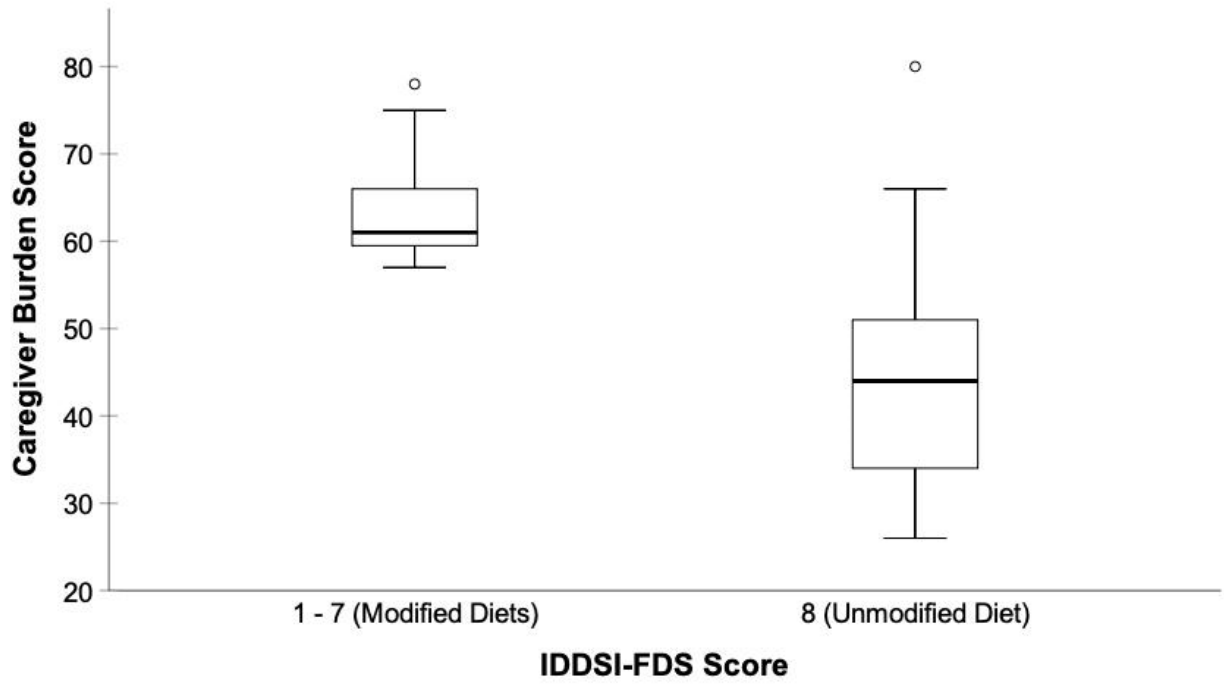
	Correlation coefficient^a	P value
Survivor appraisal of mealtime logistics impact	.547	.002**
Survivor appraisal of social impact	.401	.017
Spouse appraisal of mealtime logistics impact	.758	<.001**
Spouse appraisal of social impact	.389	.021
Dyadic congruence of mealtime logistics impact	-.241	.113
Dyadic congruence of social impact	-.259	.092
IDDSI-FDS	-.647	<.001**
SWAL-QOL	-.566	.001**
SIS – Physical subscale	-.218	.265
SIS – Cognitive subscale	.078	.692
SIS – Emotional subscale	-.300	.120
SIS – Social subscale	-.318	.099

**Significant correlation after adjustment for multiple comparisons.

^a Spearman's Rho (r_s) was calculated for all variables except for IDDSI-FDS, which used point-biserial correlation (r_{pb}).

IDDSI-FDS = International Dysphagia Diet Standardisation Initiative – Functional Diet Scale; *SIS* = Stroke Impact Scale; *SWAL-QOL* = Swallowing-Related Quality of Life scale





Discussion

The purpose of this study was to better understand the relationships between dysphagia-related caregiver burden, individual and dyadic appraisal of dysphagia's impact on mealtimes, and survivor-specific disease characteristics among stroke survivors and their spouses. Increased burden was significantly associated with greater care recipient- and caregiver-perceived impact of dysphagia on mealtime logistics, increased diet restrictiveness, and decreased swallowing-related quality of life. Further, dysphagia-related caregiver burden was not found to be associated with measures of dyadic appraisal congruence or measures of stroke impact/severity.

In accordance with the WHO-ICF framework for third-party disability (WHO, 2001), individual factors from both care recipients (e.g., stroke survivors) and informal caregivers (e.g., spouses) can contribute to caregiver burden. This interdependency between a patient's disease severity and their partner's well-being is apparent in the current data in that dysphagia-related caregiver burden was associated with both survivor and spouse appraisal of the impact of dysphagia on mealtime logistics as well as diet restrictiveness (IDDSI-FDS) and swallowing-related quality of life (SWAL-QOL). Significantly, while these variables were determined to be related, the directionality of cause and effect between them could not be ascertained. For example, increased burden could increase a caregiver's negative appraisal of disease impact or greater impact could increase burden. The WHO-ICF framework also highlights that environmental, or contextual, factors influence well-being and the impact of a disease on daily life. The current results indicated that caregiver burden and both survivor and spouse appraisals were associated with IDDSI-FDS scores, suggesting that the work associated with diet restrictiveness may be one potential contextual factor impacting disability.

Contrary to what was initially hypothesized, we did not find increased dyadic incongruence to be associated with burden. It is possible that dysphagia impacts caregivers and the caregiving dyad differently than other chronic health conditions (e.g., Roberto, Gold, & Yorgason, 2004; Robbins et al., 2013). It is also plausible that the relationship(s) between congruence and burden vary across disease severity. Notably, the more restrictive the survivor's diet was, the more likely it was that the dyad agreed on the impact of dysphagia on mealtimes. This is aligned with previous literature suggesting that dyads' congruence in appraising the impact of a condition increases with time as the condition becomes more severe (Poort et al., 2016). Such findings warrant the need for further exploration into congruence as a potential contributing factor to caregiver burden among dyads with less restrictive diets. In the present study, there was a wide range in levels of burden among caregivers whose care recipients had no dietary restrictions (IDDSI-FDS score of 8; see Figure 3); however, due to the small sample size, there was not enough spread across various factors of interest, including diet restrictiveness, to explore differences in burden among only the less diet-restricted dyads. Another possible explanation for the lack of association between dyadic congruence and burden is that dyadic management may be the operative variable for dysphagia-related caregiver burden, not couples' perceptual congruence of dysphagia impact. The Dyadic Theory of Illness Management (Lyons & Lee, 2018) posits that both dyadic appraisal and dyadic management contribute to overall dyadic health. We did not specifically target dyadic management with the questions asked and thus could not discern whether caregivers were shouldering more of the work associated with managing their partners' dysphagia symptoms or if there was an imbalance in the amount that each partner is involved in actively managing dysphagia symptoms. This imbalance in management may occur regardless of disease severity and despite caregivers and survivors

agreeing on dysphagia severity, ultimately contributing to burden among certain dyads. The potential increased importance of management over appraisal could be supported by the finding that perception of dysphagia's impact on mealtime logistics was associated with burden, but not the perception of dysphagia's impact on the social aspects of mealtime. Unfortunately, there were too few participants at each IDDSI-FDS level to explore this hypothesis in the present study, but this should be a target of future investigations.

This study also found that stroke severity was not associated with dysphagia-specific caregiver burden across any of the domains of stroke impact measured. Our finding that diet restrictiveness and decreased swallowing-related quality of life, but not stroke severity predicted increased caregiver burden does align with the prior research indicating that dysphagia is an independent predictor of caregiver burden even when controlling for various other health conditions (Namasivayam-MacDonald & Shune, 2020; Shune & Namasivayam-MacDonald, 2020b). The previous work, though, examined dysphagia's impact on more general caregiver burden, and was unable to discern the exact specifics of how dysphagia may impact such burden. Our current results contribute to this literature by suggesting that there are aspects of caregiver burden that are specific to dysphagia, evidenced by the finding that stroke severity was not associated with the measure of dysphagia-related caregiver burden. Thus, it will be important for future work to continue to explore how burden specific to the care of dysphagia fits in with and contributes to more global caregiver burden.

Perhaps unexpectedly, the results also revealed that perceived impacts on mealtime logistics, but not social impacts, were associated with increased caregiver burden. This finding could be due to an effort on the part of both care recipients and caregivers to maintain their usual social environments around mealtimes despite the presence of dysphagia. While couples did

report certain impacts on the social aspects of mealtimes, such as eating in restaurants less often, most couples reported that they still enjoyed eating their meals together with each other. This continuation of the daily norm for most of their meals could facilitate the maintenance of the value and quality partners feel about their relationship to their spouse, thus mitigating some of the associated burden. As noted by Shune and Namasivayam-MacDonald (2020b), changes in the daily act of eating socially have the potential to negatively impact the spousal relationship, but this did not appear to be the case in either their previous study or the present study. Further, the food itself may be less important than with whom the food is being consumed. This finding has been echoed in other studies of spousal relationships in the context of dysphagia, which have revealed that not only do partners feel similarly close as they did prior to the stroke, but that families intentionally shift focus toward the importance of socialization during meals (Nund et al., 2014b; Johansson & Johansson, 2009). Such positivity despite documented change (e.g., dyads report spending less time with friends, but indicate enjoyment and appreciation of spending time with each other), could be one mechanism supporting resiliency, or the ability to adapt effectively in the presence of significant adversity (Luthar et al., 2000). Among other factors, resiliency is facilitated through social support, interpersonal interactions that meet an individual's emotional and functional needs, and perceived self-efficacy and ability to manage care-related stressors (Korpershoek et al., 2011; Shaffer et al., 2016; Southwick et al., 2005). Thus, while dysphagia may change the social aspects of mealtimes, these changes appear to not contribute to caregiver burden and, in fact, dyads may counter these changes with increased closeness as a marker of resiliency.

Clinical Implications

The results of the current study point to the importance of understanding the perspectives and experiences of patients with dysphagia in addition to their caregivers. Given the interrelatedness of care recipient and caregiver outcomes, managing dysphagia ultimately requires a focus on the health and quality of life of both the care recipient as well as their family. Specifically, by addressing the identification and, potentially, reduction of caregiver burden, speech-language pathologists (SLPs) can maximize the effectiveness of their treatments. The results of the current study suggest a number of areas that SLPs can attend to that may be associated with increased caregiver burden. By understanding how patients and their caregivers feel about dysphagia management, particularly as related to the day-to-day logistics of managing the dysphagia, SLPs can help pinpoint areas for potential intervention. For example, are patients and family members comfortable with modifying textures? Do they feel like they have access to appropriate foods? Is the family having difficulty managing additional costs associated with dysphagia? Specifically addressing these needs as part of treatment and with the help of a multidisciplinary team can help to reduce the burden of care placed on the family, which, in turn, can improve outcomes for both the caregiver and the patient.

Additionally, it would be worthwhile to check in on the at-home dysphagia management process specifically for a family where the care recipient is on a highly restrictive diet. As supported by the results here, increased diet restrictiveness was associated with increased caregiver burden. Further, increased diet restrictiveness was associated with increased perceived impacts on dysphagia management (mealtime logistics). Thus, informal caregivers of care recipients on highly restrictive diets may be most vulnerable. Education on the benefits and possible challenges associated with diet modifications and modified food preparation for patients

and their caregivers can be beneficial and may also increase patient compliance with diet texture recommendations, promoting eating safety (Krekeler et al., 2020; Rosenvinge & Starke, 2005; Sabate, 2003). Further, the wide range of caregiver burden among those whose care recipient eats an unmodified diet also points to the importance of following up with care recipients and caregivers about their challenges and feelings about dysphagia management regardless of the level of diet modification. These follow-up appointments may be particularly important to their continued ability to maintain adequate nutrition and manage the social and mealtime logistics impacts of dysphagia for themselves and their caregivers.

Limitations

The present study was a preliminary investigation into the relationships between caregiver burden, diet restrictiveness, swallowing-related quality of life, and dyadic health. There were a number of limitations that could have impacted the results. Firstly, the relatively small sample size with few participants reporting an IDDSI-FDS score below 7 prevented subgroup analyses based on varying degrees of diet restrictiveness. Further, no instrumental assessments of dysphagia were completed limiting the ability to draw conclusions related to dysphagia severity. Interestingly, the present study revealed a large range of experiences in survivors who were on “regular” diets, defined in this study as those with an IDDSI-FDS score of 8. Future work should thus continue to explore dysphagia-related caregiver burden using more objective measures of dysphagia severity.

Secondly, at the time of data collection there were no validated measures available to quantify caregiver burden, mealtime appraisal, or dyadic congruence as they relate to dysphagia. The survey used in this study was created by the investigators for this study and is not validated or norm-referenced. The questionnaire was intended to be used only for the purposes of this

study and thus factor analysis was not completed. It is possible that the subsequent scale was not unidimensional despite good internal consistency. Further, there was no cut-off score indicating how many mealtime questionnaire items a couple had to disagree on to classify as “incongruent.” This could account for some of the more surprising outcomes. Notably, a validated tool measuring dysphagia-related caregiver burden was recently developed (Shune et al., 2020); further investigation is needed into the use of such a tool for both research and clinical purposes in order to better understand the impact of spousal caregiver burden in this population.

Finally, due to the wide dissemination methods, it is difficult to ascertain whether the participants in this study are reflective of the larger population with post-stroke dysphagia and their spousal caregivers. Due to non-response bias, it could be that couples with higher levels of burden are less likely to participate in a voluntary research study or that survivors with higher levels of dysphagia severity do not respond at the same rate as those with less severe dysphagia due to concomitant health issues or other factors related to accessibility of study participation.

Conclusion

In summary, factors related to dysphagia-related caregiver burden are multifactorial and include both survivor (e.g., IDDSI-FDS, SWAL-QOL, perceived impact of dysphagia on mealtime logistics) and spousal (e.g., perceived impact of dysphagia on mealtime logistics) variables. The results of this preliminary investigation support the need to incorporate aspects of counseling and family-centered care into our management practices, a growing area of interest for SLPs. These results suggest a need for SLPs to support spousal caregivers of patients with post-stroke dysphagia in order to mitigate the detrimental effects of disruptions to the social and logistic aspects of mealtimes. It is important for SLPs and other healthcare professionals to understand the lived experience of both patients and their families in order to better understand

each individual's unique environmental and personal factors that could influence their plan of care. Follow-up visits with patients with post-stroke dysphagia and their spousal caregivers may be helpful to address questions and concerns surrounding mealtimes that may negatively impact the client and/or their spousal caregiver. Ultimately, maximizing patient outcomes requires a more intentional focus on caregiver outcomes as a regular component of treatment delivery.

Acknowledgements

We thank Amanda Morano-Villhauer, MS, CCC-SLP, BCS-S for her valuable contributions to the study and survey design. Portions of this manuscript were presented as an oral presentation at the 2020 Dysphagia Research Society Annual Meeting (virtual meeting).

References

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *The Journal of the American Medical Association, 311*(10), 1052-1060.
- Arnold, M., Liesirova, K., Broeg-Morvay, A., Meisterernst, J., Schlager, M., Mono, M. L., El-Koussy, M., Kagi, G., Jung, S., & Sarikaya, H. (2016). Dysphagia in acute stroke: Incidence, burden and impact on clinical outcome. *PLoS One, 11*(2).
- Bentur, N., Sternberg, S., Shuldiner, J., Dwolatzky, T. (2015). Feeding tubes for older people with advanced dementia living in the community in Israel. *American journal of Alzheimers disease and other dementias, 30*, 165–172.
- Byun, E., & Evans, L. K. (2015). Concept analysis of burden in caregivers of stroke survivors during the early poststroke period. *Clinical nursing research, 24*(5), 468-486.
- Chari, A., Engberg, J., Ray, K., & Mehrotra, A. (2015). The opportunity costs of informal elder-care in the United States: New estimates from the American Time Use Survey. *Health Services Research, 50*(3), 871-882.
- Choi-Kwon, S., Kim, H. S., Kwon, S. U., & Kim, J. S. (2005). Factors affecting the burden on caregivers of stroke survivors in South Korea. *Archives of physical medicine and rehabilitation, 86*(5), 1043-1048.
- DeVellis, R. F. (2012). *Scale development: Theory and application*. Sage Publications.
- Foley, N. C., Martin, R. E., Salter, K. L., & Teasell, R. W. (2009). A review of the relationship between dysphagia and malnutrition following stroke. *Journal of rehabilitation medicine, 41*(9), 707-713.

- Duncan, P. W., Wallace, D., Lai, S. M., Johnson, D., Embretson, S., & Laster, L. J. (1999). The Stroke Impact Scale Version 2.0 Evaluation of Reliability, Validity, and Sensitivity to Change. *Stroke*, *30*(10), 2131-2140.
- George L. K & Gwyther L. P. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist*, *26*(3), 253–259. <https://doi.org/10.1093/geront/26.3.253>.
- Isaac, V., Stewart, R., & Krishnamoorthy, E. S. (2011). Caregiver burden and quality of life of older persons with stroke: A community hospital study in South India. *Journal of applied gerontology*, *30*(5), 643-654
- 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. & Johansson, U. (2009). Relatives' experiences of family members' eating difficulties. *Scandinavian Journal of Occupational Therapy*, *16*, 25-32.
- 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
- Klinke, M. E., Wilson, M. E., Hafsteinsdóttir, T. B., & Jónsdóttir, H. (2013). Recognizing new perspectives in eating difficulties following stroke: A concept analysis. *Disability and Rehabilitation*, *35*(17), 1491–1500. <https://doi.org/10.3109/09638288.2012.736012>

- Krekeler, B. N., Vitale, K., Yee, J., Powell, R., & Rogus-Pulia, N. (2020). Adherence to dysphagia treatment recommendations: A conceptual model. *Journal of Speech, Language, and Hearing Research*, 1-17.
- Korpershoek, C., Van der Bijl, J., & Hafsteinsdóttir, T. B. (2011). Self-efficacy and its influence on recovery of patients with stroke: A systematic review. *Journal of Advanced Nursing*, 67(9), 1876-1894.
- LaManna, J. B., Unruh, L., Chisholm, L., Pericles, P., & Fotovvat, H. (2020). Perceptions of health and well-being among older adult caregivers: Comparisons of current caregivers with former and never caregivers. *Geriatric Nursing*.
- Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71(3), 543-562.
- Lwi, S. J., Ford, B. Q., Casey, J. J., Miller, B. L., & Levenson, R. W. (2017). Poor caregiver mental health predicts mortality of patients with neurodegenerative disease. *Proceedings of the National Academy of Sciences*, 114(28), 7319-7324.
- Lyons, K. S., & Lee, C. S. (2018). The theory of dyadic illness management. *Journal of Family Nursing*, 24(1), 8–28. <https://doi.org/10.1177/1074840717745669>
- Mann, G., Hankey, G. J., & Cameron, D. (1999). Swallowing function after stroke: Prognosis and prognostic factors at 6 months. *Stroke*, 30(4), 744–748.
<https://doi.org/10.1161/01.str.30.4.744>
- Martino, R., Foley, N., Bhogal, S., Diamant, N., Speechley, M., & Teasell, R. (2005). Dysphagia after stroke: Incidence, diagnosis, and pulmonary complications. *Stroke*, 36(12), 2756–2763. <https://doi.org/10.1161/01.STR.0000190056.76543.eb>
- McCarthy, M. J., & Lyons, K. S. (2015). Incongruence between stroke survivor and spouse

perceptions of survivor functioning and effects on spouse mental health: A mixed-methods pilot study. *Aging & Mental Health*, 19(1), 46–54.

<https://doi.org/10.1080/13607863.2014.913551>

McHorney C. A., Robbins J., Lomax K., Rosenbek J. C., Chignell K., Kramer A. E., & Bricker D. E. (2002). The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III. Documentation of reliability and validity. *Dysphagia*, 17(2), 97-114.

Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., ... American Heart Association Statistics Committee and Stroke Statistics Subcommittee. (2015). Heart disease and stroke statistics-2015 update: A report from the American Heart Association. *Circulation*, 131(4), e29-322.

<https://doi.org/10.1161/CIR.000000000000152>

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>

Namasivayam-MacDonald, A. & 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. doi:10.1016/j.gerinurse.2019.06.008

Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014a). Application of the International Classification of Functioning, Disability, and Health (ICF) to people with dysphagia following non-surgical head and neck cancer management. *Dysphagia*, 29, 692 - 703.

- Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014b). Carers' experiences of dysphagia in people treated for head and neck cancer: A qualitative study. *Dysphagia*, *29*, 450-458.
- 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.
- 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.
- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, *18*(2), 250-267. <https://doi.org/10.1037/0882-7974.18.2.250>
- Poort, H., Peters, M., Gielissen, M., Verhagen, C., Bleijenberg, G., van der Graaf, W., Wearden, A. J., & Knoop, H. (2016). Fatigue in Advanced Cancer Patients: Congruence Between Patients and Their Informal Caregivers About Patients' Fatigue Severity During Cancer Treatment with Palliative Intent and Predictors of Agreement. *Journal of Pain and Symptom Management*, *52*(3), 336 – 344.
- Pucciarelli, G., Lee, C. S., Lyons, K. S., Simeone, S., Alvaro, R., & Vellone, E. (2019). Quality of Life Trajectories Among Stroke Survivors and the Related Changes in Caregiver Outcomes: A Growth Mixture Study. *Archives of Physical Medicine and Rehabilitation*, *100*(3), 433-440.e1. <https://doi.org/10.1016/j.apmr.2018.07.428>
- Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke*, *4*(4), 285-292.

- Riviere, S.; Gillette-Guyonnet, S.; Andrieu, S.; Nourhashemi, F.; Lauque, S.; Cantet, C.; Salva, A.; Frisoni, G.; Vellas, B. (2002). Cognitive function and caregiver burden: Predictive factors for eating behaviour disorders in Alzheimer's disease. *Journal of Geriatric Psychiatry, 17*, 950–955.
- Robbins, M. L., Mehl, M. R., Smith, H. L., & Weihs, K. L. (2013). Linguistic indicators of patient, couple, and family adjustment following breast cancer. *Psycho-Oncology, 22*(7), 1501–1508. <https://doi.org/10.1002/pon.3161>
- Roberto, K., Gold, D., & Yorgason, J. (2004). The influence of osteoporosis on the marital relationship of older couples. *Journal of Applied Gerontology, 23*(4), 443-456.
- Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. New York: Basic Books.
- Rosenvinge, S. K. & Starke I.D. (2005). Improving care for patients with dysphagia. *Age and Ageing; 34*, 587–93.
- Sabaté, E., & Sabaté, E. (Eds.). (2003). *Adherence to long-term therapies: Evidence for action*. World Health Organization.
- 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. <https://doi.org/10.1001/jama.282.23.2215>
- 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>
- Shaffer, K. M., Riklin, E., Jacobs, J. M., Rosand, J., & Vranceanu, A. M. (2016). Psychosocial

- resiliency is associated with lower emotional distress among dyads of patients and their informal caregivers in the neuroscience intensive care unit. *Journal of Critical Care*, 36, 154-159.
- Shune, S., & Namasivayam-MacDonald, A. M. (2020a). Caregiver burden in dysphagia: Moving beyond the physiological impairment. *Perspectives of the ASHA Special Interest Groups*, 5(5), 1282-1289.
- Shune, S., & Namasivayam-MacDonald, A. M. (2020b). 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., Resnick, B., Zarit, S. H., & Namasivayam-MacDonald, A. M. (2020). Creation and initial validation of the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) screening tool. *American Journal of Speech-Language Pathology*, 29(4), 2131-2144.
- Smithard, D. G., O'Neill, P. A., Park, C. L., Morris, J., Wyatt, R., England, R., & Martin, D. F. (1996). Complications and outcome after acute stroke: does dysphagia matter?. *Stroke*, 27(7), 1200-1204.
- Smithard, D., Smeeton, N., & Wolfe, C. (2007). Long-term outcome after stroke: Does dysphagia matter? *Age and Ageing*, 36, 90-94.
- Southwick, S. M., Vythilingam, M., & Charney, D. S. (2005). The psychobiology of depression and resilience to stress: implications for prevention and treatment. *Annual Review of Clinical Psychology*, 1, 255-291.
- Steele, C. A., Namasivayam-MacDonald, A. M., Guida, B. T., Cichero, J. A., Duivesteyn, J., Hanson, B., Lam, P., & Riquelme, L. F. (2018) Creation and initial validation of the

International Dysphagia Diet Standardisation Initiative Functional Diet Scale. *Archives of Physical Medicine and Rehabilitation*, 99(5), 934-944.

Takizawa, C., Gemmell, E., Kenworthy, J., & Speyer, R. (2016). A systematic review of the prevalence of oropharyngeal dysphagia in stroke, Parkinson's disease, Alzheimer's disease, head injury, and pneumonia. *Dysphagia*, 31(3), 434-441.

Torti, F. M., 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.

World Health Organization. (2001). *International classification of functioning, disability, and health*. Geneva: World Health Organization.

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. *Journal of the American Medical Association Internal Medicine*, 176(3), 372-379.

<https://doi.org/10.1001/jamainternmed.2015.7664>

Figure Legends/Captions

Figure 1. Scatterplot with regression line depicting the relationship between dysphagia-related caregiver burden and survivor appraisal of dysphagia's impact on mealtime logistics.

Figure 2. Scatterplot with regression line depicting the relationship between dysphagia-related caregiver burden and caregiver appraisal of dysphagia's impact on mealtime logistics.

Figure 3. Boxplots depicting the relationship between dysphagia-related caregiver burden and IDDSI-FDS scores. Outliers (values between 1.5 and 3 times the interquartile range) are indicated with open circles.

Figure 4. Scatterplot with regression line depicting the relationship between dysphagia-related caregiver burden and SWAL-QOL scores.