

POST-STROKE DYSPHAGIA'S IMPACT ON SURVIVORS  
AND SPOUSAL CAREGIVERS: THE IMPORTANCE OF  
PERCEPTUAL CONGRUENCE

by

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Previous studies have shown a link between survivors' stroke severity and family caregiver burden, however other factors may contribute to this burden. Burden specific to post-stroke dysphagia and the consequences of incongruence between care recipient and care partner in their perception of the impacts of the care recipient's dysphagia are potential variables that are unexplored. The present study aimed to determine the role of partner congruence in the perceived mealtime impacts of post-stroke dysphagia on caregiver burden. Twenty-seven spousal dyads consisting of a stroke survivor experiencing post-stroke dysphagia and their spousal caregiver were surveyed concerning their perceptions of the logistical and social impacts of dysphagia on mealtimes and stroke and dysphagia severity. Dyadic congruence in perceptions of mealtime logistical impacts, but not mealtime social impacts, was associated with increased caregiver burden. Additionally, increased survivor dysphagia severity and caregivers' perceived mealtime logistical impacts were also associated with increased caregiver burden. These results can guide speech-language pathologists and other health professionals in their interventions for clients with dysphagia and their families.

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## **Introduction**

### **Definition of Clinical Problem**

Dysphagia, or difficulty swallowing, is a prevalent and debilitating health condition, affecting roughly 1 in 25 adults in the United States annually (Bhattacharyya, 2014) and 8 percent of the population worldwide (Cichero et al., 2013). Common causes of dysphagia include stroke, traumatic brain injury, and progressive neurologic diseases, such as Parkinson's or ALS. Some signs of dysphagia are, but are not limited to, the inability to recognize food, the inability to control saliva or food in the mouth, coughing during or after eating, frequent pneumonia, and weight loss (Logemann, 1998). These challenges can lead to complications such as malnutrition, dehydration, choking, and death as a result of recurrent aspiration pneumonia (Logemann, 1998). The complications of dysphagia are not only physical but are also social in nature. Those with dysphagia often experience decreased social participation and increased anxiety and depression as a result of their condition (Karvonen-Guitierrez, Robis, Fowler, Terrell, Gruber, & Duffy, 2008; Klinke, Wilson, Halfsteinsdottir, & Jonsdottir, 2013). Because of these additional social impacts, dysphagia contributes not only to the physical and financial costs of a chronic illness, but also to the psychosocial costs, dramatically impacting morbidity, mortality, and quality of life.

### **Dysphagia After Stroke**

As the population of the United States and the rest of the world rapidly ages, a growing number of the people will experience age-related illnesses such as stroke and dementia. Unfortunately, stroke is a very common cause of dysphagia (Mann, Hankey,



& Cameron, 1999, 2000; Martino et al., 2005). During a stroke, reduced blood flow to specific parts of the brain can damage the pathways that control the cognitive and physical aspects of eating and swallowing, including both the more voluntary (e.g., chewing) and the more involuntary components of the swallow (Daniels & Huckabee, 2014). It is estimated that up to 65% of stroke survivors experience dysphagia in at least the acute stage of recovery, and that in 50% of these survivors, dysphagia persists for at least six months (Mann, Hankey, & Cameron, 1999, 2000; Martino et al., 2005). Since stroke is the leading cause of long-term disability in the United States, the annual nation-wide incidence of stroke-related dysphagia is in the tens of millions (Mozaffarian et al., 2015). Dysphagia is likely a strong contributor to the biopsychosocial impacts of stroke and has been linked to lower quality of life and increased mortality rates among survivors of stroke and other causes of dysphagia, such as head and neck cancer (Karvonen-Gutierrez et al., 2008; Klinke, Wilson, Hafsteinsdottir, & Jonsdottir, 2013; Nguyen et al., 2005).

### **Caregiver Burden**

Following a stroke, a patient may be discharged directly from the hospital to their family residence. In this case, a relative often serves as their informal, primary caregiver if they continue to require assistance with everyday tasks. Significantly, informal caregiving has become a primary source of care provision for older adults (Chari et al., 2015). Nearly 44 million Americans serve as caregivers of older adults or individuals with disabilities, saving the healthcare system approximately \$470 billion per year (Reinhard et al., 2019). Unfortunately, the shift in role from relative to primary caregiver and the increased demands placed on these individuals can lead to significant

caregiver burden and burnout. Caregiver burden is defined as any additional emotional, financial, or physical stress a person experiences as a result of caring for another person (Namasivayam-MacDonald & Shune, 2018). The consequences of a high level of caregiver burden are widespread and can include an increased risk of mental illness, such as anxiety and depression, health decline, and feelings of frustration or resentment in the caregiver (McCarthy & Lyons, 2015). In addition, increased emotional burden has been found to be an independent risk factor for caregiver mortality in elderly caregivers (Schulz & Beach, 1999). In this study, two groups of older adult participants, 392 caregivers and 427 non-caregivers, were followed to measure 4-year mortality in relation to variables in the level of caregiving they performed for their spouse. After 4 years, those participants who both acted as caregivers and experienced caregiver burden passed away at rates 63% higher than non-caregivers. Conversely, participants who acted as caregivers but did not experience caregiver burden as well as those who had a spouse who required caregiving but did not personally act as their caregiver did not experience an increase in mortality risk.

Unfortunately, caregiver burden negatively impacts not only the caregiver, but also the care recipient's health and well-being (Torti, Gwyther, Reed, Friedman, & Schulman, 2004; Wolff, Spillman, Freedman, & Kasper, 2016). Though caregiving can be difficult on its own, the addition of emotional, physical, and/or financial burden ultimately adds to the likelihood of decreased caregiver health and mortality, which can negatively impact their ability to provide care. As such, it can be inferred that the consequences of high caregiver burden are often cyclical; high levels of burden can lead to poor caregiver health outcomes, which in turn can impact the level of care provided

to the care recipient, resulting in poor outcomes for their health as well. This model would suggest that patient and caregiver health outcomes are interdependent and cyclical, highlighting the importance of considering both members of the caregiving dyad.

Research has explored the interdependence of quality of life and burden specifically among stroke survivors and their caregivers. For example, Pucciarelli et al. (2019) conducted a longitudinal study of quality of life trajectories in stroke survivors as well as the burden, anxiety, and depression experienced by their informal caregivers over the course of the 12 months following a stroke. The informal caregivers were predominantly the stroke survivors' spouses and children. The study found that a stroke survivor's quality of life trajectory aligned with their informal caregiver's levels of burden, anxiety, and depression during the first year after the stroke. In other words, decreased survivor quality of life was associated with increased caregiver burden, anxiety, and depression. The authors concluded that it is important for healthcare providers to target interventions for the stroke survivor as well as the caregiver to increase positive quality of life and caregiver burden outcomes. This study showed that the quality of life of a stroke survivor and the mental health of their caregiver are interdependent and warrant increased clinical attention. However, it did not explore specifically what may contribute to increased burden, anxiety, and depression among these caregivers, important knowledge for developing appropriate clinical interventions and therapeutic targets.

Interestingly, Shune and Namasivayam-MacDonald (2020) found that spouses caring for a partner with dysphagia were 2.06 times more likely to experience emotional

burden than spousal caregivers whose partner did not have dysphagia. The researchers used the linked, longitudinal National Health and Aging Trends Study and National Study of Caregiving surveys from 422 spousal dyads to determine the specific type and extent of burden experienced by caregivers of partners with dysphagia. Seventy percent of those caregivers of individuals with dysphagia who reported feeling emotional burden rated that burden as moderate to severe, denoting a significant impact on daily life. 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.

### **Third-Party Disability and Dysphagia**

One framework used to describe spousal health interdependence in response to chronic illness is the World Health Organization's (WHO) conceptualization of "third-party disability," or disability in caregivers/family members that directly results from their loved one's chronic illness. This concept situates caregivers not just as supporters of the health of their loved one, but as patients in their own right. Incorporating the family into a patient's care management plan is important but supporting their family caregivers is just as important. Family caregivers may become patients themselves, developing illnesses of their own, if they are not supported by the healthcare professionals who are treating their loved one. A change in the patient's health status can affect the caregiver's health, which will in turn impact the patient's health. Contextual factors, such as environment, financial situation, and mental health status, surrounding the patient as well as the rest of their family will influence outcomes for everyone involved (WHO, 2001).

A number of studies have explored the third-party disability associated with dysphagia. In head and neck cancer patients, a group with high incidence of dysphagia, the impact of dysphagia on the patients' family members has been studied with a focus on third-party disability. Patients' family members have been found to experience decreased social participation and quality of life, such as interacting less often with friends and extended family and developing depression or anxiety, as an indirect result of their loved one's condition and eating capabilities (Nund, Scarinci, Cartmill, Ward, Kuipers, & Porceddu, 2014b, 2016; Patterson, Rapley, Carding, Wilson, & McColl, 2013). Building on this framework, Nund et al. (2016) used the WHO's International Classification of Functioning, Disability, and Health (ICF) to further characterize the specific third-party disability experienced by caregivers of head and neck cancer patients with dysphagia. They used data from semi-structured interviews to classify the impacts of dysphagia as reported by caregivers into the categories and sub-categories of the ICF framework, with most topics fitting under the ICF's Activities and Participation domain. This means that caregivers perceived the greatest negative impact of dysphagia, or the greatest third-party disability, to be in the Activities and Participation domain. This was the category of third-party disability most negatively affected by the care recipient's disability, which includes items such as a person's ability to complete general tasks and demands, communicate, engage in self-care, and participate in activities of community, social, and civic life (WHO, 2002). This research showed that the third-party disability experienced by caregivers of individuals with dysphagia can be widespread and that the ICF is a useful tool for describing third-party disability in this specific population. Similar findings have been observed across other studies of head

and neck cancer patients, as well as among caregivers of individuals with neurologic impairments, such as stroke and traumatic brain injury (Nund et al., 2014a).

Namasivayam-MacDonald and Shune (2018) conducted a systematic review of literature on the burden resulting from dysphagia in caregivers of older adults. While dysphagia was not the main focus of any of the four studies included in the review, dysphagia was found to be associated with increased burden across all of them. The authors' hypothesized that the third-party disability related to dysphagia as discussed in the previous literature was likely a contributor to the dysphagia-related burden observed in the four studies. The authors concluded that it was not possible to determine the prevalence or severity of dysphagia-related caregiver burden or third-party disability among caregivers of older adults from the available literature and that more research should be done to determine the specific relationship between aspects of dysphagia care and caregiver burden.

### **Dyadic Illness Management Theory**

Another related theory used to analyze and interpret spousal (or caregiver dyad) interactions in response to chronic illness is the Dyadic Illness Management Theory. Described by Lyons and Lee (2018), the Dyadic Illness Management Theory conceptualizes couple dyads as interdependent teams whose main goal is to optimize the health of both partners. The theory consists of two parts: dyadic appraisal and dyadic coping. Appraisal is how each partner perceives the illness. Lyons and Lee suggest that the amount of congruence in dyadic appraisal is more important than each individuals' separate appraisal. Dyadic management behavior is how a dyad makes decisions, manages changes in functioning and symptom severity, and goes about care

planning. In some cases, positive dyadic management behavior involves equally sharing the tasks of illness management; however, for some dyads, an unbalanced sharing of illness management tasks might lead to the most optimal dyadic health outcomes. Important to note is the lack of distinction of “patient” and “caregiver” individually; particularly in a spousal relationship of older adults, both members of the dyad may be patients and caregivers in some capacity. Rather, the focus is on the dyadic unit. It has been found that increased dyadic management behaviors and increased congruence in dyadic appraisal are protective factors for positive outcomes in the presence of chronic illness, while decreased dyadic management behaviors and increased incongruence in dyadic appraisal are risk factors for negative outcomes.

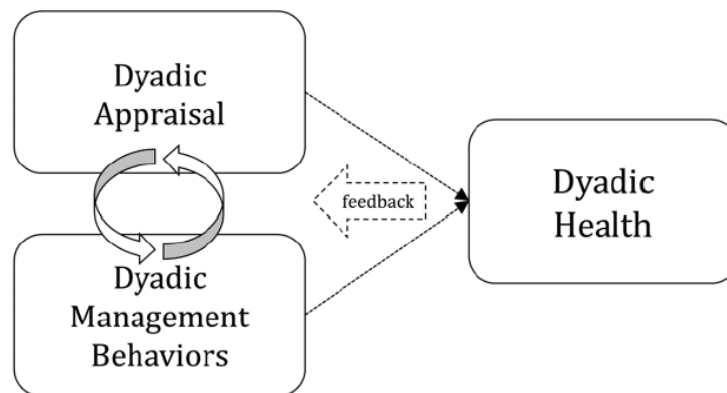


Figure 1: “Central elements of the Theory of Dyadic Illness Management” from Lyons, K. S., & Lee, C. S. (2018). The Theory of Dyadic Illness Management. *Journal of Family Nursing*, 24(1), 8-28.

Numerous studies have been conducted to identify the effect of congruence and incongruence in dyadic appraisal. For example, Roberto, Gold, and Yorgason (2004) studied heterosexual spousal dyads where the wife had been diagnosed with osteoporosis. Couples with more incongruence in their appraisals of care recipients’ daily pain levels experienced lower relationship adjustment than those couples whose

appraisals were congruent. Additionally, Robbins, Mehl, Smith, and Weihs (2013) qualitatively analyzed language used by couples when talking about their adjustment after breast cancer diagnosis and found that couples who used “we-talk” when describing the illness experienced better marital adjustment than couples who used “you-talk.” “We-talk” is language that includes the partner in descriptions of a patient’s diagnosis, such as saying, “We had an appointment with the doctor last week,” whereas “you-talk” is language that excludes the partner from the patient’s diagnosis, such as saying, “She went to see her doctor last week.” The previous dysphagia research has narrowly explored only individual-level factors contributing to third-party disability, focusing solely on the caregiver perspective with no studies on dyadic management of dysphagia or of the impact of incongruence on spousal dyads experiencing dysphagia. Further, the Dyadic Illness Management Theory has not yet been applied to management of dysphagia.



## **Purpose of Current Study**

### **Gap in Literature and Problem**

A growing body of evidence supports dysphagia's independent role in contributing to increased caregiver burden. Yet, it remains unclear how or why dysphagia increases this burden. Third-party disability as viewed through the ICF framework and the Dyadic Illness Management Theory offer insight into this relationship by suggesting that not only do the increased roles/responsibilities and decreased life participation on the part of caregiver contribute to this burden, but that aspects of the dyad as related to roles/responsibilities and participation (e.g., collaboration, congruence in perception) may be particularly important. Prior studies aimed at identifying the role of third-party disability on separate patient and caregiver outcomes have focused mainly on dysphagia in head and neck cancer patients or on other chronic conditions unrelated to dysphagia. The unique challenges associated with post-stroke dysphagia and the potential for spousal incongruence in the perceptions of the impacts of this dysphagia on caregiver health are important to add to the existing literature. Thus, a significant gap in the literature exists in connecting third-party disability and the Dyadic Illness Management Theory to caregiver and dyadic outcomes given post-stroke dysphagia. For the purposes of the current study, we focus on one aspect of this interaction: patient/caregiver incongruence in perceptions of the impact of post-stroke dysphagia on mealtime and social functioning. In addition to the important theoretical knowledge to be gained, there are important clinical implications for this research. Speech-language pathologists and other health professionals must understand

the impact of dysphagia on families in order to provide treatment that addresses the broader needs of both the patient and their family caregivers. Within the WHO's ICF model, a patient's health condition, such as dysphagia, impacts caregiver third-party disability. Yet, as describe previously, a caregiver's health and well-being can also act as contextual factors that affect the patient, similar to how a patient's financial situation or access to high-quality healthcare would (see Figure 1). Thus, to maximize health and well-being for the patient, caregiver health and well-being must be targeted as well (Nund et al., 2014c; Shune and Namasivayam-MacDonald, 2020).

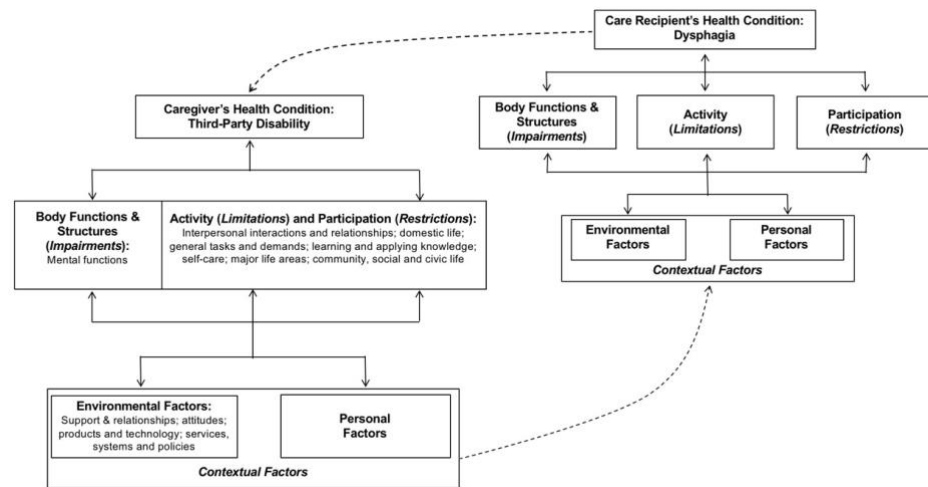


Figure 2: Application of the WHO's International Classification of Functioning, Disability, and Health framework from Namasivayam-MacDonald & Shune (2018).

In order to improve the health and well-being of these patients and caregivers, it is of clear clinical relevance to identify those factors that predict and/or contribute to resiliency and improved family well-being. Interestingly, partners who are in agreement about the impacts of dysphagia on physical as well as social functioning may be better situated to cope with the realities of the condition than partners who disagree about the

impacts, which would mirror results observed in partners dealing with other chronic conditions (Robbins et al., 2013; Roberto et al., 2004). However, it is not yet known which factors contribute to the burden associated with dysphagia and whether factors such as incongruence are similarly present in dysphagia as in other illnesses. Such information is crucial to designing more comprehensive dysphagia treatment approaches that can better address the wider impact of the individual's impairment on the individual and their caregivers.

### **Clinical Relevance of Present Study**

Speech-language pathologists (SLPs) are the health professionals responsible for the evaluation, diagnosis, and treatment of dysphagia. They are responsible for educating patients and their caregivers on ways to increase eating safety, which is one component of treatment. However, caregivers do not always feel comfortable or supported in their roles and as a result, dysphagia management may become an overwhelming part of caring for their partners (Nund et al., 2014c). In fact, dysphagia has been found to be one independent contributor to increased caregiver burden, even when controlling for other factors known to influence burden (Shune & Namasivayam-MacDonald, 2020). Further, as with any chronic illness, caregivers and family member undergo a process of learning to adapt to the new situation; some individuals demonstrate resilience and flourish, while others struggle (Rolland, 1994). As health professionals, SLPs should choose intervention models that support caregivers and that are feasible for them to implement at home, a consideration that will help more families to develop resilience in the face of a loved one's chronic illness, such as post-stroke dysphagia. This study aims to identify the relationships between various factors,

including perceptual incongruence, that could increase spousal caregiver burden in an effort to better understand couples' experiences and provide a foundation for the application of Dyadic Illness Management Theory and the International Classification of Functioning, Disability, and Health within this population.

### **Research Questions and Hypotheses**

The goal of this study is to identify areas of agreement and disagreement between patient/caregiver spouses about the perceived impact of post-stroke dysphagia on mealtimes and to examine the potential contributors to dysphagia-specific caregiver burden, particularly the associations between burden and mealtime/eating-related congruence and incongruence and dysphagia severity and stroke severity. Such information is crucial to designing more comprehensive dysphagia treatment approaches that can better address the wider impact of the individual's impairment, including the development of third-party disability in their caregivers. Specific questions that need to be addressed are: (1) On which aspects of mealtimes do patients with post-stroke dysphagia and their spousal caregivers most often agree in terms of their perception of impact? (2) Disagree? (3) What impact does perceptual incongruence have on degree of caregiver burden in the context of post-stroke dysphagia, in light of the impact of dysphagia and stroke severity? (4) What other factors contribute to dysphagia-specific caregiver burden in this population?

There are three hypotheses:

- (1) Higher levels of incongruence between partners in the perceived impact of dysphagia on the logistic and social aspects of mealtimes will correlate with higher levels of dysphagia-related caregiver burden.
- (2) Worse Swallowing Quality of Life (SWAL-QOL) and Stroke Impact Scale (SIS) scores will correlate with higher levels of dysphagia-related caregiver burden.
- (3) Dysphagia severity, as measured by IDDSI-FDS levels, will correlate with higher levels of dysphagia-related caregiver burden.

## **Methods and Procedure**

### **Participants**

Twenty-seven survivor-partner dyads participated in the study. Survivor participants were at least 18 years old, had their most recent stroke at least 3 months prior to participating, and were married to and living with their primary caregiver. Partner participants 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. Flyers were also posted in the community and shared with support groups for stroke survivors and/or individuals with dysphagia. There was an incentive in the form of a \$20 gift card for each individual who participated (\$40 total for the dyad) which was paid once both partners in a dyad had completed the survey. Demographic information for all participants is presented in Table 1.

Table 1. Demographics of study participants

Characteristic	Survivors ( <i>n</i> = 27)	Spouses ( <i>n</i> = 27)
Gender (female), <i>n</i> (%)	8 (30)	20 (74)
Age, years [mean (range)]	61.7 (33–88)	58.4 (32-86)
Race/Ethnicity, <i>n</i> (%)		
White	19 (70)	20 (74)
Hispanic/Latino	1 (4)	--
African American	7 (26)	6 (22)
Decline to answer	--	1 (4)
Work Status, <i>n</i> (%)		
Full-time	4 (15)	9 (33)
Part-time	4 (15)	10 (37)
Unemployed	4 (15)	1 (4)
Retired	15 (56)	6 (22)
Other	--	1 (4)
Education, <i>n</i> (%)		
High school	5 (19)	5 (19)
Certificate beyond high school	6 (22)	6 (22)
Some college	1 (4)	2 (7)
Bachelor's degree	8 (30)	12 (44)
Master's degree or higher	5 (19)	2 (7)
Time Since Stroke, months [mean (Q1, Q2, Q3)]	50.5 (4.5, 12, 33)	--
Stroke Type, <i>n</i> (%)		
Ischemic	10 (38)	--
Hemorrhagic	5 (19)	--
Unknown	11 (42)	--
Stroke Localization, <i>n</i> (%)		
Right	5 (19)	--
Left	7 (26)	--
Other/Unknown	15 (56)	--
Number of Strokes, <i>n</i> (%)		
One	15 (56)	--
Two	8 (30)	--

Three or more	2 (7)	--
No Response	2 (7)	--
Reported Swallowing Difficulties, <i>n</i> (%)		
Yes	21 (78)	19 (70)
No	4 (15)	6 (22)
No Response	2 (7)	2 (7)
Reported Partner Requires Help With Task, <i>n</i> (%)		
Eating		
Yes	--	11 (41)
No	--	14 (52)
No Response	--	2 (7)
Bathing		
Yes	--	14 (52)
No	--	11 (41)
No Response	--	2 (7)
Dressing		
Yes	--	10 (37)
No	--	15 (56)
No Response	--	2 (7)
Getting around inside the home		
Yes	--	6 (22)
No	--	19 (70)
No Response	--	2 (7)
Therapies Received, <i>n</i> (%)		
Speech Therapy (Speech, Language, or Voice)		
Yes	6 (22)	--
No	19 (70)	--
No Response	2 (7)	--
Speech Therapy (Swallowing)		
Yes	4 (15)	--
No	21 (78)	--
No Response	2 (7)	--
Physical Therapy		
Yes	7 (26)	--



No	18 (67)	--
No Response	2 (7)	--
Occupational Therapy		
Yes	3 (11)	--
No	22 (78)	--
No Response	2 (7)	--
Stroke Support Group Participation, <i>n</i> (%)		
Yes	6 (22)	8 (30)
No	19 (70)	17 (63)
No Response	2 (7)	2 (7)
Additional Medical Conditions Impacting Daily Life, <i>n</i> (%)		
Hypertension or heart failure	13 (48)	--
Diabetes	4 (15)	--
Back pain	4 (15)	--
Anxiety	2 (7)	--
Obesity	3 (11)	--
Allergies	1 (4)	--
Heartburn	8 (30)	--
Breathing difficulties	2 (7)	--
Bad eyesight	6 (22)	--
Osteoporosis or arthritis	2 (7)	--
Fibromyalgia	1 (4)	--
Depression	4 (15)	--
Other	7 (26)	--
None	8 (30)	--

### **Survey Development and Outcome Measures**

The data used in the current study were collected as part of a larger study exploring the impact of post-stroke dysphagia on family functioning. As part of the larger study, the stroke survivors and spousal caregivers completed surveys containing

three primary sections: (1) participant demographic information; (2) a social and logistic mealtime questionnaire, which included questions that derived an International Dysphagia Diet Standardization Initiative Functional Diet Scale (IDDSI-FDS) score (Steele et al., 2018) and (3) a relationship quality questionnaire. Two speech-language pathologists (one clinical researcher with expertise in dysphagia and one hospital-based clinician who is a board-certified specialist in dysphagia) developed the surveys. The social and logistic mealtime questionnaire included questions on the financial impacts of preparing meals for someone with dysphagia, fear of choking, feelings of embarrassment, and time spent eating socially in and out of the home, among others. For the development of the questionnaire, the International Classification of Functioning, Disability, and Health (ICF) framework was used to ensure multiple relevant domains of functioning were addressed, including the Body Functions and Activities and Participation sub-domains. Initially, a list of relevant topics across the ICF domains was taken from the head and neck cancer literature (Nund et al., 2014, 2015). Then, those categories addressing problems specific to head and neck cancer, such as decreased saliva, were excluded given the focus of the current study on stroke. The remaining domains were used to create two different surveys: one for survivors and one for spouses. Questions pertaining to other components of dysphagia-related health and functioning not addressed by the ICF were added based on the Family Systems-Illness Model (Rolland, 1994). The relationship quality questionnaire covered each partner's feelings of being included in decision-making, feelings of closeness, the ability to communicate openly, and perceived changes in the relationship following the most recent stroke, among others. Rolland's Family Systems-Illness Model (1994)

formed the basis for the questions in the section. The two speech-language pathologists along with and three survivor-spouse dyads then reviewed the surveys for content, validity, redundancy, organization, and clarity, leading to the revisions which lead to the final draft of the surveys. The final version included Likert scale, multiple choice, and open-ended question types.

In addition, the stroke survivors also completed two additional survey sections: (4) the Swallowing-related Quality of Life scale (SWAL-QOL; McHorney et al., 2002), which measures perceived dysphagia severity and dysphagia-related quality of life across sub-categories such as desire to eat, frequency of dysphagia symptoms, and perceived social and emotional impacts of dysphagia, and (5) the Stroke Impact Scale (SIS; Duncan et al., 1999), a measure of overall stroke severity. The SWAL-QOL and SIS are both validated and reliable measures. The full survivor and spouse surveys are available in the appendices.

### **Data Collection**

All procedures were approved by the University of Oregon's Institutional Review Board. Interested participants either contacted research staff for additional information or accessed the link to the online survey directly. There were both paper (via mail) and online versions of the survey available depending on participant preference. Upon completion, all survey materials were then de-identified and assigned a code; no key was retained that could link the code to participants' names. For surveys returned by mail, the compensation form with contact information was removed and stored separately from the surveys. For participants who completed the online version, they were redirected to a separate page following completion of the survey that allowed

them to enter contact information necessary to receive compensation. The compensation page and survey page were not linked. The survivor survey took most participants between 30 and 45 minutes to complete and the spouse survey took most participants between 15 and 30 minutes. Participants, especially stroke survivors, could receive help from family, partner, or research staff in completing the survey, if they needed help writing their answers, for instance.

## **Variables of Interest**

### *Congruence Scores*

Congruence scores for the mealtime questionnaires were calculated by assigning a value to each response on the 6-point Likert scale. For example, “Strongly Disagree” was assigned a score of 1 and “Strongly Agree” was assigned a score of 6. Then, negatively worded questions were reverse scored (i.e., subtracted the value from 7) such that a higher score could be interpreted as a more negative response, or more burden. For those questions where it was available, “N/A” was assigned a score of 0. Corresponding questions on the spouse and survivor questionnaires appeared in a different order and were therefore matched before comparison. Each partner’s total scores were calculated to determine their perceived impact of dysphagia on the social and logistical aspects of mealtimes. To calculate absolute continuous congruence scores, the absolute value of the difference between the two partners’ scores were calculated, with a higher score indicating a lower level of congruence (or higher level of incongruence). For example, a congruence score of 13 meant that the couple had answered the questionnaire in a way that differed by 13 points overall on the Likert

scale. Conversely, a score of 0 either meant that the couple agreed perfectly on every question or that their number disagreements were evenly distributed across the partners.

#### *SWAL-QOL Scores*

Survivors' Swallowing Quality of Life scores were used as a proxy measure for dysphagia severity. They were scored according to a standard scoring algorithm such that each item on the survey is given a score from 0 to 4 (worst to best). Subscale scores were calculated using a standardized scoring algorithm in which the sum of scores for each scale is expressed as a percentage of the maximum possible score for that scale. A total SWAL-QOL score was then derived by averaging the subscale scores. For the current study, the fatigue and sleep subscales were excluded from this total given their lack of specificity for measuring dysphagia-specific quality of life. As per standard protocol, the physical symptom inventory was also not calculated into the total score.

#### *Stroke Impact Scale Scores*

Survivors' Stroke Impact Scale scores were used as a proxy measure for stroke severity. Scores were calculated using a standardized scoring algorithm where each item on the survey was given a score from 1 to 5 (worst to best). These items scores were summed to form section scores that were then summed to form subscales scores in the areas of physical, cognitive, emotional, and social functioning. Subscale scores were expressed as a percentage of the maximum possible score for each area of functioning. Total SIS scores were derived by averaging the four subscale scores.

### *IDDSI-FDS Scores*

To calculate an additional proxy measure of dysphagia severity, survivors' level of diet restrictiveness as measured by their IDDSI-FDS scores were calculated using the IDDSI-FDS table. Based on the survivors' answers to two questions, one regarding the texture of their food and one regarding the consistency of their beverages they regularly consume, IDDSI food (3-7) and drink (0-4) levels were derived. Using the IDDSI-FDS table, these two levels were inputted to produce a single IDDSI-FDS score indicative of the survivors' level of diet restrictiveness. The IDDSI-FDS table can be found in Appendix C.

### *Spousal Burden*

A spousal burden score was calculated based on spouses' answers to all 21 mealtime questions except "My partner enjoys eating," "It is easy to find foods appropriate for my partner's diet at home," and "I feel like I nag my partner during meals." These questions were not included in the spousal burden score because based on the Cronbach's Alpha calculation, these questions did not group with the others in a meaningful way. Each item was scored based on a 6-point Likert scale with 1 indicating the least impact and 6 indicating the most impact. Then, negatively worded questions were reverse scored (i.e., subtracted the value from 7) such that a higher score could be interpreted as a more negative response, or more burden. For those questions where it was available, "N/A" was assigned a score of 0. A sum was taken for all included items to create a total burden score where a higher score indicated a higher level of caregiver burden.

## Statistical Analysis

Descriptive statistics were used to evaluate the demographic data from the participants. Cronbach's Alphas were calculated to determine which questions for the mealtime and relationship-related sub-sections grouped together in a meaningful way. This calculation informed which questions were included in the final measures for the impact of dysphagia on the social/logistic aspects of mealtimes; the calculated impact and continuous congruence scores were then used for the remaining analyses. In order to assess the agreement, or congruence, between partners in their rating of dysphagia's impacts, intraclass correlation coefficients were calculated. The strength of congruence was labeled as follows:  $\leq 0.40$  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. Finally, Spearman's Rho correlation coefficients were calculated in order to determine the impact of congruence and dysphagia and stroke severity on caregiver burden. To adjust for multiple comparisons, the Holm's step-down procedure was applied to this analysis.

## Results

### Reliability of Study Specific Measures

Based on the calculations of internal consistency, the final mealtime logistics subscale consisted of 4 items with a total possible score ranging from 0 to 24 ( $\alpha = .720$  for survivors,  $\alpha = .693$  for spouses). This scale was used to determine the level of congruence between survivors' and spouses' perceptions of impact on mealtime logistics. The final mealtime social subscale consisted of 6 items with a total possible score ranging from 0 to 36 ( $\alpha = .776$  for survivors,  $\alpha = .613$  for spouses). This scale was used to determine the level of congruence between survivors' and spouses' perceptions of impact on social aspects of meals. The final dysphagia-related spousal burden subscale consisted of 20 items with a total possible score ranging from 0 to 120 ( $\alpha = .865$ ).

### Spousal Congruence

It was hypothesized that all couples would disagree at least once on the impact of dysphagia on mealtime-related activities. There was moderate incongruence between survivors' and spouses' perceptions of dysphagia's impact on the logistical and social aspects of mealtimes. Neither the survivors nor the spouses consistently reported a greater impact of dysphagia on mealtimes (logistics:  $t(25) = 1.167, p = .254$ ; social:  $t(25) = 0.602, p = .553$ ).

### Relationship Between Congruence, Caregiver Burden, and Disease Severity

Table 2 presents the results of the correlation analyses between caregiver burden and spousal congruence, dysphagia severity, and stroke severity.



Table 2. Correlations between (a) dysphagia-related spousal burden and (b) congruence and survivor-specific disease characteristics.

	Spearman's Rho ( $r_s$ )	<i>P</i> value
Mealtime Logistics Congruence	-.494	.004**
Mealtime Social Congruence	-.235	.119
IDDSI-FDS	-.654	<.001**
SWAL-QOL	-.354	.035
SIS – Physical Subscale	-.187	.176
SIS – Social Subscale	-.326	.049
SIS – Cognitive Subscale	.270	.087
SIS – Emotional Subscale	-.138	.246

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

The first hypothesis, that higher levels of incongruence between partners in the perceived impact of dysphagia on the logistic and social aspects of mealtimes will correlate with higher levels of dysphagia-related caregiver burden was partially correct. A significant negative relationship existed between burden and mealtime logistics congruence ( $r_s = -.494$ ,  $p = .004$ ). This meant that increased burden was associated with decreased agreement in survivor-spouse perceptions of dysphagia's impact on the logistic aspects of mealtimes. Figure 3 depicts a scatterplot of this relationship. However, burden was not associated with mealtime social congruence ( $p = .119$ ). This meant that the congruence in impacts on logistic, but not social aspects of mealtimes were related to burden.

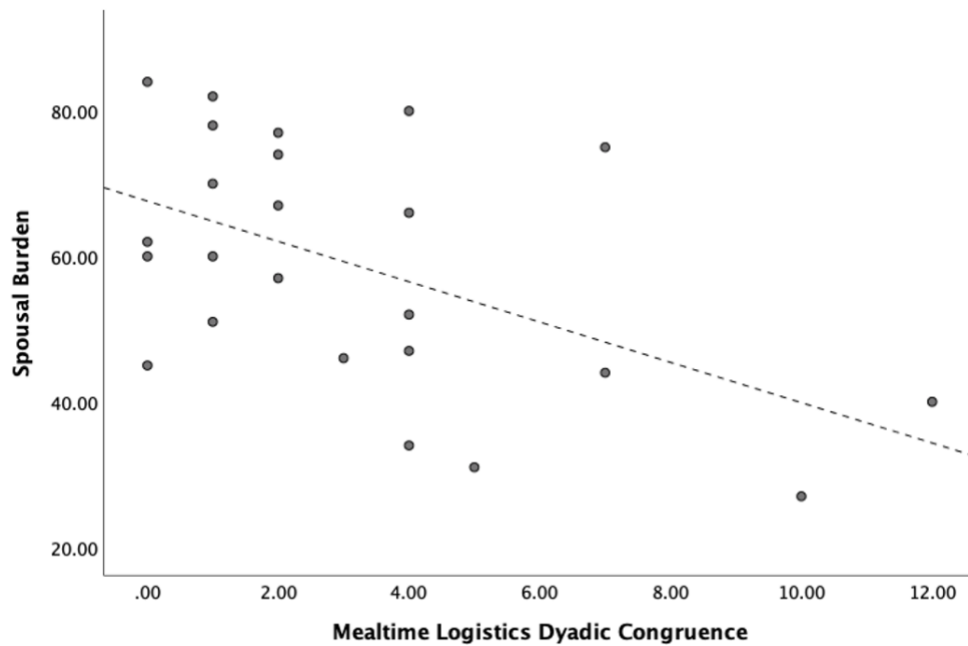


Figure 3: Scatterplot with regression line depicting the relationship between spousal burden and congruence of mealtime logistical impact perception.

The second hypothesis, that worse Swallowing Quality of Life (SWAL-QOL) and Stroke Impact Scale (SIS) scores will correlate with higher levels of dysphagia-related caregiver burden was incorrect. The SWAL-QOL measured survivor-reported dysphagia-related quality of life and the SIS measured survivor-reported stroke impact and severity. Notably, dysphagia-related burden was not associated with self-reported measures of dysphagia-related quality of life ( $p = .035$ ) or measures of stroke impact severity (SIS-physical:  $p = .176$ ; SIS-social:  $p = .049$ ; SIS-cognitive:  $p = .087$ ; SIS-emotional:  $p = .246$ ).

The third hypothesis, that dysphagia severity, as measured by IDDSI-FDS levels, would correlate with higher levels of dysphagia-specific caregiver burden was correct. IDDSI-FDS was also negatively associated with burden ( $r_s = -.654, p < .001$ ). This meant that increased burden was associated with lower IDDSI-FDS scores,

indicating a higher degree of diet restrictiveness (as a proxy for a higher degree of dysphagia severity). Figure 4 shows a scatterplot of this negative linear trend.

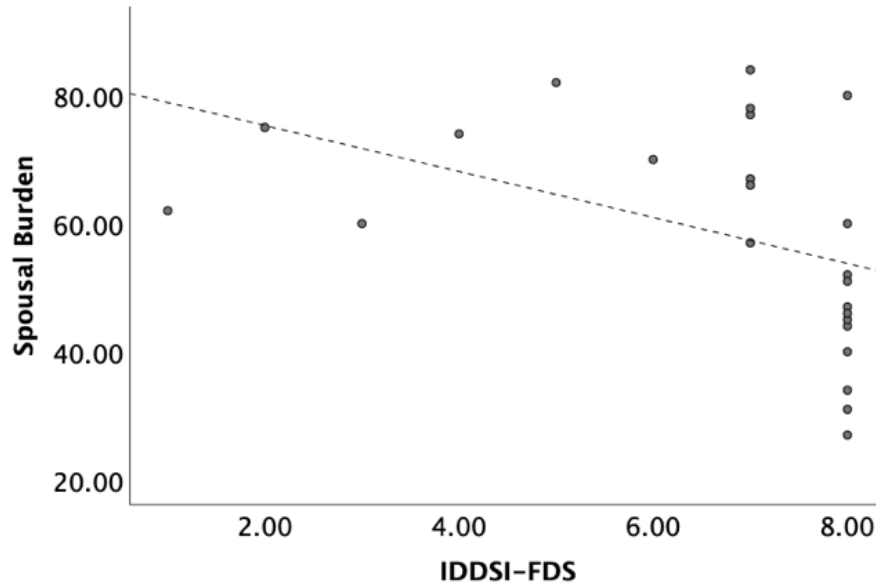


Figure 4: Scatterplot with regression line depicting the relationship between spousal burden and survivor diet modification level as measured by IDDSI-FDS score.

### **Additional Results**

In addition to the results of the hypotheses, the results of the study produced findings not anticipated prior to statistical analysis. Post-hoc analyses were conducted and found a significant positive correlation between reported levels of spousal burden and both spouses' and survivors' perceptions of logistical impacts of mealtimes as a result of dysphagia (spouses:  $r_s = .619$ ,  $p = <.001$ ; survivors:  $r_s = .485$ ,  $p = .005$ ). Figure 5 shows a scatterplot of this positive linear trend.

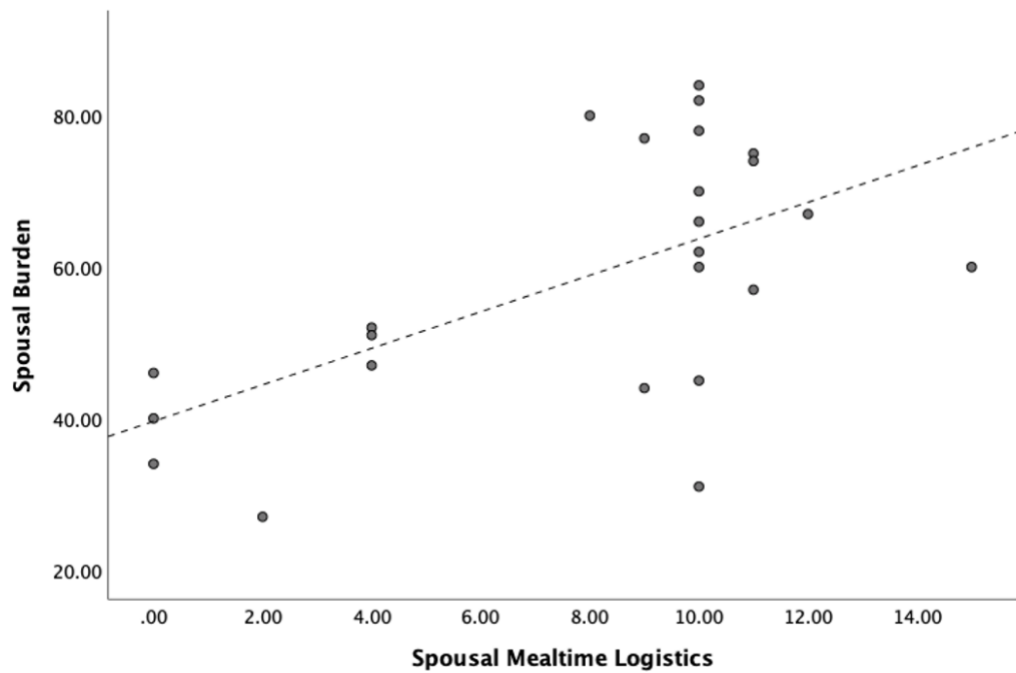


Figure 5: Scatterplot with regression line depicting the relationship between spousal burden and spouse-perceived mealtime logistical impacts.

There was also a significant positive correlation between IDDSI-FDS score and mealtime logistics congruence scores ( $r_s = .483, p = .005$ ). This means that higher levels of diet restrictiveness were associated with higher congruence scores and vice versa, indicating a positive relationship between dysphagia severity and level of congruence between partners. This means that the more severe a survivor’s dysphagia, the more likely both partners are to perceive that the impacts on logistic aspects of mealtimes are similar.

Finally, there was a significant negative relationship between spouse, but not survivor mealtime logistic impact scores and survivors’ IDDSI-FDS scores (spouses:  $r_s = -.834, p < .001$ ; survivors:  $r_s = -.244, p = .110$ ). This means that for spouses, but not for survivors, the level of dysphagia severity correlated with the perceived impact on logistic aspects of mealtimes, indicating a source of burden for spouses.

## Discussion

This study aimed to determine areas of incongruence in care dyads' perceptions of mealtime impacts as a result of post-stroke dysphagia and to determine the potential influence of this incongruence on spousal caregiver burden. It was hypothesized that:

- (4) Higher levels of incongruence between partners in the perceived impact of dysphagia on the logistic and social aspects of mealtimes will correlate with higher levels of dysphagia-related caregiver burden.
- (5) Worse Swallowing Quality of Life (SWAL-QOL) and Stroke Impact Scale (SIS) scores will correlate with higher levels of dysphagia-related caregiver burden.
- (6) Dysphagia severity, as measured by IDDSI-FDS levels, will correlate with higher levels of dysphagia-related caregiver burden.

In response to these hypotheses, this study found, firstly, that higher levels of incongruence between partners in the perceived impact of dysphagia on logistic, but not social aspects of mealtimes correlated with higher levels of dysphagia-related caregiver burden. Secondly, worse SWAL-QOL and SIS scores did not correlate with higher levels of caregiver burden. Thirdly, dysphagia severity, as measured by IDDSI-FDS level, was found to correlate with higher levels of dysphagia-related caregiver burden.

Most fundamentally, the results showed that incongruence between spouses in perceived mealtime logistical impacts, but not social impacts, was associated with increased caregiver burden. This does not mean that mealtime social impacts did not increase caregiver burden, just that incongruence between partners in their perception of these kinds of impacts did not increase burden. However, perceived mealtime logistical

impact congruence was associated with increased caregiver burden. This difference in results between logistical and social aspects of mealtimes could be due to a number of factors. Primarily, logistic aspects of mealtimes are actual tasks where the caregiver may be spending additional time or money to accommodate the logistical needs of their spouse, with items such as “it is easy to find foods appropriate for my diet at home.” However, the social aspects of mealtimes may affect both partners equally. This portion of the survey included items such as “I enjoy eating with my partner” and “I socialize with my family as often as I did prior to my stroke.” This difference between logistical and social aspects of meals could be the result of spouses conceptualizing logistical aspects as “caregiving” tasks, such as preparing a different meal for their partner than they do for themselves, while they conceptualize social aspects of meals, such as how often they go out to eat, as “non-caregiving” parts of daily life.

Additionally, this study suggests that there is increased caregiver burden specific to the presence of dysphagia that is not solely tied to stroke severity, a factor which has previously been shown to increase caregiver burden. Notably, none of the subscale scores for the SIS were found to be significantly associated with the dysphagia-related burden measured here. The SWAL-QOL scale and IDDSI-FDS were used as proxy measures for survivors’ dysphagia severity, and the SIS was used to measure stroke severity, but only the IDDSI-FDS scores were significantly negatively associated with spousal burden. This could be because the SWAL-QOL scale and SIS measured survivors’ reported dysphagia-related quality of life and stroke impact, respectively, which were subjective measures, while the IDDSI-FDS objectively described the textures of food and drink survivors were capable of consuming. For this reason,

IDDSI-FDS may have been a more accurate proxy for actual dysphagia severity, while the SWAL-QOL scale and SIS were measures of survivors' views on how their dysphagia and stroke symptoms, regardless of severity, affected their lives.

Because both the SWAL-QOL and SIS are subjective measures, it could be that survivors underreported their perceived dysphagia-related quality of life and stroke impact severity or that they inaccurately perceived the severity of the impact of dysphagia and stroke symptoms on their daily lives. If this was the case, these discrepancies could be due to declined cognitive status in the stroke survivors, a factor not measured by this study. Results may have been different if spouses were asked to complete the SWAL-QOL and SIS on behalf of survivors in addition to survivors' own responses. This may have led to a more complete picture of the level of incongruence in perceived symptom severity between partners. However, it should be noted that since there was no consistent or significant difference between the survivor and spouse groups in terms of perceived mealtime impact, it is also likely that there would be no such difference in survivor and spouse SWAL-QOL and SIS scores if spouses had reported on these measures.

This study's finding that neither spouses nor survivors consistently reported higher levels of impact than did the other group directly contrasts previous research into patient and caregiver congruence dynamics. For instance, in a study of terminal cancer patients on palliative care and their informal caregivers, Poort et al. (2016) found that caregivers consistently overestimated patients' levels of clinically significant fatigue. They suggested that this overestimation on the part of caregivers could contribute to increased caregiver burden due to the incorrect perception that the patient required more

care than they actually did. This was not a consistent pattern in the present study, where roughly equal numbers of caregivers versus survivors reported a higher level of mealtime impact than their partner. This could be due to the wide range in dysphagia severity, stroke severity, and age among the sample participants. Lyons & Lee (2018) highlight the heterogeneity of disease appraisal between members of dyads and among different dyads experiencing the same illnesses. It could be that the present sample of participants successfully captured this heterogeneity, resulting in inconclusive patterns in the direction of incongruence.

Despite the differences in patterns of directional incongruence, there were some similarities between the results of the present study and the Poort et al. (2016) study. In their longitudinal study, congruence did not change significantly over time, such that caregiving dyads who were congruent at the beginning maintained their congruence. There was a trend for dyads to become more congruent over time, which in the case of terminal cancer patients meant they became more congruent in their estimates of patient fatigue as the patients' fatigue symptoms became more severe as their disease progressed. This suggests a relationship between patient symptom severity and increased congruence between partners in their appraisal of the patients' symptoms. This relationship between symptom severity and increased congruence was true in the present study, as worsened IDDSI-FDS scores, a measure of dysphagia severity, correlated with mealtime logistical impact congruence scores. In the present study, the group sizes were not large enough to reach significance when comparing multiple variables simultaneously, such as congruence score and dysphagia severity. However, though it is possible that there were more survivors with greater dysphagia severity in



dyads with higher congruence, the present sample did not allow for these types of analyses to reach statistical significance, and this information is, therefore, unknown.

### **International Classification of Functioning, Disability, and Health (ICF)**

The ICF is a useful model for describing the spouses' experiences unearthed in the present study pertaining to the specific aspects of caring for a partner with dysphagia that are associated with caregiver burden. As previously mentioned, caregivers of adults with dysphagia are at risk for caregiver burden attributable specifically to their partners' dysphagia symptoms. This study showed that the contextual factors of dysphagia severity, spouse-perceived impacts on mealtime logistics, and incongruent perception of mealtime logistics between partners, that differ between couples are associated with increased caregiver burden. Within the ICF model, these contextual factors could impact caregivers' own mental and physical health, activities, and social participation which in turn could have a negative impact on survivors' health, activities, and social participation.

The idea that the health status of a care recipient could impair, limit, or restrict the functioning of their caregiver is called third-party disability. Based on this definition, caregiver burden is a type of third-party disability if it impairs, limit, or restricts the daily functioning of the caregiver. Understanding what aspects of caregiving are likely to lead to burden is helpful for therapists who could help to minimize the causes of these burdens or address them as they come up with their clients. In the Poort et al. (2016) study, higher levels of caregiver fatigue and strain were associated with less congruence in estimations of patient fatigue level,

demonstrating the cyclical relationship between care recipients and caregivers. A similar phenomenon occurred in the present study, where there was a significant negative correlation between reported spousal caregiver burden and mealtime logistical impact congruence scores. This could suggest that caregivers who experience more burden are more likely to over- or under-estimate the impact of their partners' symptoms and the impact of those symptoms than caregivers experiencing less burden. This is in direct contrast to the opposite possibility that less congruence causes an increase in spousal caregiver burden, although this relationship could be bi-directional, highlighting the cyclical relationship between care recipients' health and caregivers' health that leads to third-party disability in informal caregivers.

Nund et al. (2016) aimed to map qualitative data from caregivers of individuals with dysphagia secondary to head and neck cancer onto the ICF model, finding links to the model in the area of Activities and Participation. This finding is in contrast to the result in the present study that spouses' perceptions of mealtime logistical impacts, but not social impacts correlated with increased spousal burden. The Activities and Participation domain of the ICF include impacts such as functional status, mobility, and interpersonal interactions. These impacts seem to align equally with the logistical and social aspects of mealtimes, yet only the impacts in the logistical aspects of mealtimes were associated with increased caregiver burden. It could be that for spouses caring for a partner with post-stroke dysphagia, only certain aspects of the Activities and Participation domain are likely to lead to the development of third-party disability.

## **Dyadic Illness Management Theory**

The finding that greater incongruence in partners' perception of dysphagia's impact on mealtime logistics was associated with greater spousal caregiver burden supports that one of the core behaviors proposed in the Dyadic Illness Management Theory (Lyons & Lee, 2018), dyadic appraisal, is a source of caregiver burden in this population. In the present study, incongruence in perception of this one aspect of daily life, mealtime logistics, was associated with elevated levels of caregiver burden. However, incongruence in perception of the social aspects of mealtimes was not associated with increased burden. This suggests that incongruence in the area of mealtime logistics, but not social aspects of mealtimes is a contextual factor that imparts risk for caregiver burden.

These results relate to the results of McCarthy and Lyons (2015), where it was found that stroke survivor and spouse incongruence scores for physical functioning were associated with increased depressive symptoms in spousal caregivers. While the present study measured only dysphagia-specific caregiver burden and did not measure spouses' levels of emotional burden as measured by the presence of depressive symptoms, it is important to note that in both studies, higher levels of incongruence were associated with increased burden of some kind in spousal caregivers. Thus, the lack of dyadic appraisal appears to be a key factor in the development of caregiver burden in couples experiencing the after-effects of a stroke.

McCarthy and Lyons (2015) shared a result with Poort et al. (2016) in that in both studies, caregivers rated patient symptoms as worse than the patient rated their own symptoms, a result not found in present study. It should be noted that the present

study did not directly measure caregivers' perception of patient symptoms, only the impact of the patients' symptoms on spouse and patients' perceptions mealtimes. This could be the reason for the difference in dyadic appraisal between this study and the two prior studies. It seems that perception of the impact of dysphagia is different than perception of the symptom itself and yields different congruence scores when measured separately. This finding suggests that there are different relevant measures of dyadic appraisal that could help clinicians better understand the source of incongruence, such as disease severity appraisal and disease impact appraisal.

The other key component described in Dyadic Illness Management Theory, dyadic management, was not directly addressed in this study, but warrants mentioning because of the recursive relationship between dyadic appraisal, dyadic management, and overall dyadic health. For couples who have higher incongruence in their appraisal of the impact of dysphagia on mealtimes, dyadic management skills, such as collaboration in decision-making and care planning, may act as a protective factor against caregiver burden or negative health outcomes for both partners. This is an important relationship for health professionals to understand, as they can capitalize on the protective factors present in a particular dyad's situation.

As mentioned, the Theory of Dyadic Illness Management emphasizes the heterogeneity of dyads, pointing out the lack of an "average" care recipient-caregiver dyad. Building on a dyad's strengths while scaffolding their areas of weakness should be a goal of intervention in populations with post-stroke dysphagia. For instance, if a couple shows weakness in the area of dyadic appraisal through high incongruence in their perception of symptom severity or symptom impact, a therapist might emphasize

the need for shared treatment goals between the partners in order to help lessen their incongruent appraisals. This, in turn, could encourage dyadic management behaviors such as increased communication, shared decision-making, and balanced time spent actively managing the condition, as feasible.

### **Limitations**

This study presented a number of limitations that could have impacted the results, providing suggestions for future research to allow a better understanding of the relationship between post-stroke dysphagia and caregiver burden. Primarily, the sample size in this study was relatively small, at just 27 couples. The use of a larger sample could allow for separating couples into categories based on the direction of incongruence in their perceptions of mealtime impacts. For example, couples where the stroke survivor perceived impacts as more severe than spouses may behave differently than couples where spouses perceived the impacts as more severe than survivors and may have implications for the development of spousal burden.

A larger sample size would also allow for a more comprehensive analysis of the impact of variables on the type (financial, emotional, physical, etc.) and severity of caregiver burden. For instance, there could be a stark difference in the kinds of burden associated with caring for a younger adult versus an older adult with post-stroke dysphagia. A larger sample size would allow for grouping in such a way that these differences yield significant results. This study's participant group consisted almost entirely of older adults, which could account for the significance of the results.

Another limitation of this study was the lack of spouses' perception of survivors' quality of life and stroke impact. Only survivors answered the SWAL-QOL

and SIS questionnaires but comparing spouses' answers about survivors to survivors' own answers might yield a more comprehensive analysis of dyadic congruence in disease symptom appraisal, providing more information about the sources of caregiver burden in this population.

Finally, this study was conducted partially via an anonymous online survey, which lead to problems with certainty in the accuracy of data collection. Because the online version of the survey was shared with various stroke support groups online, anyone who found the link could answer the survey. The result of this format was a deluge of responses that, based on the incompleteness of the answers, appeared to be fake. These responses were followed-up on via email, and all of these kinds of responses were eventually removed from analysis, a time-consuming process that highlighted the flaws in online surveys. While this format did allow for the collection of data from a wide geographical area (the entire United States), the uncertainty in the validity of many of the responses caused problems during the data collection phase. Despite weeding out the obviously fake responses, there is always the possibility with an anonymous online survey that someone could fabricate answers that appeared believable enough to be included in the final data set, resulting in erroneous results.

### **Future Research**

More research should be done to gain a better understanding of the specific contributors to caregiver burden in families affected by post-stroke dysphagia. Specifically, it is important to determine what amount of overall caregiver burden is tied to dysphagia-related burden and what amount is the result of other sources of burden. With larger sample sizes, the relationship between burden and a larger variety of

individual- and dyadic-variables could be explored, allowing for a clearer picture of the scope of the problem of dysphagia-specific caregiver burden.

This research should also expand to include dysphagia-related burden in non-spousal caregivers, such as adult children of older adults with post-stroke dysphagia and parents of younger adults with post-stroke dysphagia. There may be specific, but patterned differences between the sources and type of burden experienced by these groups.

Another fruitful avenue for future research will be in quantifying the short- and long-term benefits of incorporating patients' care partners in dysphagia management teams. A better understanding of the longitudinal impact of dyadic health practices and interventions designed to improve dyadic health practices on patient and partner health outcomes for families touched by post-stroke dysphagia will lead to best practice recommendations that will benefit the care of patients with dysphagia of many etiologies and their caregivers.

## **Conclusion and Clinical Implications**

This questionnaire-based study surveyed 27 spousal dyads in order to better understand the role of inter-partner perceived mealtime impact incongruence, dysphagia severity, and stroke severity on levels of dysphagia-related spousal caregiver burden in caregivers of adults with post-stroke dysphagia. It utilized the Swallowing-related Quality of Life (SWAL-QOL) scale and Stroke Impact Scale (SIS), in conjunction with a mealtime impact questionnaire, to find correlations between these measures and levels of caregiver burden in spouses. It was found that higher levels of incongruence between partners in perceived impacts to mealtime logistics as a result of stroke survivors' dysphagia was associated with higher levels of caregiver burden. Additionally, dysphagia severity as measured by the IDDSI-FDS, but not as measured by the SWAL-QOL scale or stroke severity as measured by the SIS, was also associated with higher levels of caregiver burden.

Clinicians working with couples experiencing post-stroke dysphagia should take note of the specific challenges associated with caring for a spouse with dysphagia, implementing interventions that address the challenges of both the patient and their caregiving spouse. Assessing couples' congruence in their appraisal of both the patients' disease severity and the impact of their symptoms is important for a comprehensive understanding of areas of disagreement that could lead to burden as evidenced by prior research utilizing the International Classification of Functioning, Disability, and Health (ICF). Addressing these areas of concern early could prevent some of the caregiver burden associated with caring for a spouse with dysphagia, preventing third-party disability in the caregiver, and in turn supporting dyadic illness



appraisal and management and optimal health outcomes for both members of the caregiving dyad.

## Glossary

**Congruence:** agreement between partners.

**Dysphagia:** any swallowing disorder. May be characterized by difficulties at any level of the swallow, such as in the mouth, tongue, pharynx (throat), larynx, etc.

**International Classification of Functioning, Disability, and Health (ICF):** contextual framework for describing health while taking into account environmental factors around the individual and their caregiver(s).

**International Dysphagia Diet Standardisation Initiative Functional Diet Scale (IDDSI-FDS):** framework providing consistency in describing food and drink texture and thickness.

**Stroke Impact Scale (SIS):** a valid and reliable measure of perceived impact of stroke. The scale is administered to a person who has had a stroke to determine the amount they believe the stroke has impacted various aspects of their life, including physically, socially, emotionally, etc.

**Speech-language pathologist:** a health professional who may work in a variety of settings, including but not limited to hospitals, nursing homes, private practice, and home health. Their job is to diagnose and treat communication disorders, such as stuttering, childhood apraxia of speech, and specific language impairments, and swallowing disorders (dysphagia).

**Swallowing Quality of Life (SWAL-QOL):** a valid and reliable measure of perceived dysphagia severity. The measure is administered to a person who has had a stroke to determine the amount they believe their swallowing disorder (dysphagia) has negatively impacted their life emotionally, physically, relationally, etc.

**Theory of Dyadic Illness Management:** framework to describe the ways in which partners work together to appraise and manage illness in a way that maximizes health outcomes for both partners.

# Appendices

## Appendix A: Survivor Questionnaire

Thank you for your willingness to participate in this research study entitled. Taking part in this study is entirely voluntary and all responses will be kept strictly confidential. All of the paperwork should take about 45-60 minutes or less to complete. The majority of questions are multiple choice to facilitate the process for you, but in many cases you will have the opportunity to elaborate further and we will certainly appreciate any insights that you can offer us that you choose to share. We look forward to learning more about your experiences as a stroke survivor.

This survey is intended for adult stroke survivors living with a partner/spouse who are experiencing any type of eating, chewing, or swallowing difficulties (including changes in taste or sensation).

This study is being conducted with the University of Oregon Institutional Review Board approval. If at any time you have questions, concerns, or comments, please do not hesitate to contact Samantha Shune, Principal Investigator, at sshune@uoregon.edu or by phone at (541) 346-7494.

### Demographic and Background Information

1. What is your gender?
  - a. Male
  - b. Female
  - c. Other
2. What is your race/ethnicity? (You may select more than one)
  - a. African American
  - b. American Indian/Alaska Native
  - c. Asian
  - d. Hispanic/Latino
  - e. Native Hawaiian or Other Pacific Islander
  - f. White
  - g. Decline to Report
3. How old are you? \_\_\_\_\_ years
4. What is your current relationship status?
  - a. Married or living with a partner
  - b. Separated or divorced
  - c. Widowed
  - d. Never Married
11. Did your neurologist or family doctor provide any information about the changes you might expect as a result of your stroke?
  - a. Yes
  - b. No
12. Were you given information on stroke prevention or warning signs of a stroke by your physician or other medical professional?
  - a. Yes
  - b. No
13. Where are you currently staying overnight?
  - a. Acute care (hospital)
  - b. Skilled nursing facility
  - c. Long term care facility
  - d. Own residence/home
  - e. Other (please indicate): \_\_\_\_\_

14. Are you currently receiving any of the following therapies?

	Yes	No
Speech therapy for speech, language or voice		
Speech therapy for swallowing		
Physical therapy		
Occupational therapy		

15. Did you receive any of the following services prior to your current stroke?

	Yes	No
Speech therapy for speech, language or voice		
Speech therapy for swallowing		
Physical therapy		
Occupational therapy		

16. Do you currently have problems with chewing or swallowing?
  - a. Yes
  - b. No

5. What is your current employment status?
  - a. Retired
  - b. Working full-time
  - c. Working part-time
  - d. Unemployed
  - e. Other
6. Select the highest level of education you have completed.
  - a. No schooling completed
  - b. Completed 8<sup>th</sup> grade
  - c. High school graduate (high school diploma or equivalent)
  - d. Certificate or diploma beyond high school level
  - e. Bachelor's degree
  - f. Master's, professional, or doctoral degree
7. Including your most recent stroke, how many strokes have you had?
  - a. 1 stroke
  - b. 2 strokes
  - c. 3 or more strokes
8. What was the date of your most recent stroke (month/date/year)?
9. What was the type of your most recent stroke?
  - a. Ischemic
  - b. Hemorrhagic
  - c. Unknown or unsure
10. What was the location of your most recent stroke?
  - a. Left side of brain
  - b. Right side of brain
  - c. Front of brain
  - d. Brainstem
  - e. Other (please specify): \_\_\_\_\_
  - f. Unknown or unsure
17. Did you have problems chewing or swallowing before your current stroke?
  - a. Yes
  - b. No
 If **yes**, please describe the problems you had.
18. Have you ever participated in a stroke support group?
  - a. Yes
  - b. No
19. Please select any additional medical conditions that, in your opinion, currently impact your daily life (e.g., impact your ability to participate in desired activities, require you to modify aspects of your day).
  - a. Hypertension
  - b. Diabetes
  - c. Back pain
  - d. Anxiety
  - e. Obesity
  - f. Allergies
  - g. Heartburn
  - h. Breathing difficulties
  - i. Bad eyesight
  - j. Osteoporosis or arthritis
  - k. Fibromyalgia
  - l. Depression
  - m. Asthma
  - n. Other (please list): \_\_\_\_\_

**Relationship-Related Questions**

For each of the following statements, please indicate the extent to which you agree or disagree. Consider how you are currently feeling at this moment in time.

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
Since my stroke, I feel isolated.						
Since my stroke, I feel depressed.						
Since my stroke, I do not feel like my typical self.						
My stroke has negatively impacted my relationship with my partner/ significant other.						
My stroke has negatively impacted my relationship with other immediate family members.						
My stroke has negatively impacted my relationship with my friends and/or my involvement in the community.						
I feel as close to my partner as I did before my stroke.						
I am able to show my partner as much care/affection as I did before my stroke.						
I can talk as directly and openly with my partner as I did before my stroke.						

- Has your family's overall mood changed since your stroke?
  - Yes
  - No
 If **yes**, how?

- What are the current strengths of your relationship with your partner/significant other?

- In what ways could your relationship be made stronger?

- Have your household responsibilities changed since your stroke?
  - Yes
  - No

If **yes**, what things did you do before that someone else now does for you?

If **yes**, what things do you do now that you did not do before?

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
I feel involved in discussions about my care as related to my stroke.						
I feel comfortable talking about my stroke with my partner.						
I feel comfortable sharing feelings related to my stroke with my partner.						
My stroke has negatively impacted my participation in joint activities with my partner.						

**Mealtime-Related Questions**

For each of the following statements, please indicate the extent to which you agree or disagree. Consider how you are currently feeling at this moment in time. If a statement does not apply to you, indicate "N/A".

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree	N/A
I enjoy eating.							
I enjoy eating with my partner.							
I enjoy eating with my family.							
I enjoy eating out (e.g., at restaurants, with friends).							
My partner enjoys eating meals with me.							
I eat with my family as often as I did prior to my stroke.							
I am embarrassed to eat in front of others.							
I am frustrated by my allowable food choices.							
It is easy to find foods appropriate for my diet (e.g., modified food textures, thickened liquids) at home.							
It is easy to find foods appropriate for my diet (e.g., modified textures, thickened liquids) outside of home.							
I am bothered by reminders about "how to eat" during mealtimes.							
My foods appear appetizing.							
I am afraid of choking during meals.							

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree	N/A
It is difficult to find foods I like.							
I get enough to eat.							
Eating feels like work.							
I socialize with <b>my partner</b> during mealtimes as frequently as I did prior to my stroke.							
I socialize with <b>my family</b> during mealtimes as frequently as I did prior to my stroke.							
I socialize with <b>my friends</b> during mealtimes as frequently as I did prior to my stroke.							
It takes me longer to complete my meal than my companions.							
I believe my swallowing abilities will improve.							
I know what strategies work best for me to eat and swallow safely.							
I feel confident in my ability to use the strategies needed for me to eat and swallow safely.							
I understand why I need a modified diet and/or thickened liquids.							
Mealtime-/eating-related costs have increased since my stroke.							
My mealtime-/eating-related roles have changed since my stroke.							

1. Who prepares most of the meals in your household?
  - a. Self
  - b. Partner/significant other
  - c. Child
  - d. Other family caregiver
  - e. Hired help
  - f. Other
2. Did you prepare your own meals prior to your stroke?
  - a. Yes
  - b. No
3. Have you been given a diagnosis of dysphagia or swallowing problems?
  - a. Yes
  - b. No (if no, continue with question 4)

- If **yes**:
- i. Is it difficult to modify your foods or liquids to the correct consistency at home?
    1. Yes
    2. No
 If **yes**, please explain.
  - ii. How much additional time, on average, does it take to prepare your meals?
    1. It doesn't take any extra time to prepare my meals.
    2. 1-15 min
    3. 16-30 min
    4. 31-45 min
    5. 46 min or more
  - iii. Were you given any information on dysphagia (swallowing problems) or dysphagia diets prior to leaving the hospital?
    1. Yes
    2. No
 If **yes**, who gave you this information?
    1. Doctor
    2. Speech-language pathologist
    3. Dietician
    4. Nurse
    5. Other health professional

- iv. If your swallowing was evaluated while in the hospital, were you given any education about swallowing following the exam by your speech-language pathologist or radiologist?
    1. Yes
    2. No
  - v. Do you feel like you were given enough information prior to leaving the hospital on preparing meals safely at home?
    1. Yes
    2. No
  - vi. Do you follow the recommendations and guidelines that your speech-language pathologist or physician gave you?
    1. Yes
    2. No
 If **no**, why do you not follow the recommendations (select all that apply)?
    1. Too difficult.
    2. It would take too much time.
    3. I did not understand the recommendations.
    4. I do not think I have any problems swallowing.
    5. Other (please specify): \_\_\_\_\_
  - vii. Have you participated in a support group for swallowing difficulties?
    1. Yes
    2. No
4. Other than swallowing, do you have any problems that impact eating or mealtimes? Please select all that apply.
- a. Difficulty feeding yourself
  - b. Dentures don't fit
  - c. No dentures
  - d. Missing teeth
  - e. Get tired easily
  - f. Other (please specify): \_\_\_\_\_

**Important note:** We understand that you may have a number of physical problems. Sometimes it is hard to separate these from swallowing difficulties, but we hope that you can do your best to concentrate **only** on your **swallowing problem**. Thank you for your efforts in completing this questionnaire.

1. Below are some general statements that people with **swallowing problems** might mention. In the last month, **how true** have the following statements been for you?

*(circle one number on each line)*

	Very much true	Quite a bit true	Somewhat true	A little true	Not at all true
Dealing with my swallowing problem is very difficult.	1	2	3	4	5
My swallowing problem is a major distraction in my life.	1	2	3	4	5

2. Below are some aspects of day-to-day eating that people with **swallowing problems** sometimes talk about. In the last month, **how true** have the following statements been for you?

*(circle one number on each line)*

	Very much true	Quite a bit true	Somewhat true	A little true	Not at all true
Most days, I don't care if I eat or not.	1	2	3	4	5
It takes me longer to eat than other people.	1	2	3	4	5
I'm rarely hungry anymore.	1	2	3	4	5
It takes me forever to eat a meal.	1	2	3	4	5
I don't enjoy eating anymore.	1	2	3	4	5

3. Below are some physical problems that people with **swallowing problems** sometimes experience. In the last month, **how often** have you experienced each problem as a result of your swallowing problem?

(circle one number on each line)

	Almost always	Often	Sometimes	Hardly ever	Never
Coughing	1	2	3	4	5
Choking when you eat food	1	2	3	4	5
Choking when you take liquids	1	2	3	4	5
Having thick saliva or phlegm	1	2	3	4	5
Gagging	1	2	3	4	5
Drooling	1	2	3	4	5
Problems chewing	1	2	3	4	5
Having excess saliva or phlegm	1	2	3	4	5
Having to clear your throat	1	2	3	4	5
Food sticking in your throat	1	2	3	4	5
Food sticking in your mouth	1	2	3	4	5
Food or liquid dribbling out of your mouth	1	2	3	4	5
Food or liquid coming out your nose	1	2	3	4	5
Coughing food or liquid out of your mouth when it gets stuck	1	2	3	4	5

4. Next, please answer a few questions about how your **swallowing problem** has affected your diet and eating in the last month.

(circle one number on each line)

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
Figuring out what I can and can't eat is a problem for me	1	2	3	4	5
It is difficult to find foods that I both like and can eat.	1	2	3	4	5

8. Think about your social life in the last month. How strongly would you agree or disagree with the following statements?

(circle one number on each line)

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
I do not go out to eat because of my swallowing problem.	1	2	3	4	5
My swallowing problem makes it hard to have a social life.	1	2	3	4	5
My usual work or leisure activities have changed because of my swallowing problem.	1	2	3	4	5
Social gatherings (like holidays or get-togethers) are not enjoyable because of my swallowing problem.	1	2	3	4	5
My role with family and friends has changed because of my swallowing problem.	1	2	3	4	5

9. In the last month, **how often** have you experienced each of the following physical symptoms?

(circle one number on each line)

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Feel weak?	1	2	3	4	5
Have trouble falling asleep?	1	2	3	4	5
Feel tired?	1	2	3	4	5
Have trouble staying asleep?	1	2	3	4	5
Feel exhausted?	1	2	3	4	5

10. Do you now take any food or liquid through a feeding tube?

(circle one)

No ..... 1

Yes ..... 2

5. In the last month, **how often** have the following statements about communication applied to you because of your **swallowing problem**?

(circle one number on each line)

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
People have a hard time understanding me.	1	2	3	4	5
It's been difficult for me to speak clearly.	1	2	3	4	5

6. Below are some concerns that people with **swallowing problems** sometimes mention. In the last month, **how often** have you experienced each feeling?

(circle one number on each line)

	Almost always	Often	Sometimes	Hardly ever	Never
I fear I may start choking when I eat food.	1	2	3	4	5
I worry about getting pneumonia.	1	2	3	4	5
I am afraid of choking when I drink liquids.	1	2	3	4	5
I never know when I am going to choke.	1	2	3	4	5

7. In the last month, how often have the following statements **been true** for you because of your **swallowing problem**?

(circle one number on each line)

	Always true	Often true	Sometimes true	Hardly ever true	Never true
My swallowing problem depresses me.	1	2	3	4	5
Having to be so careful when I eat or drink annoys me.	1	2	3	4	5
I've been discouraged by my swallowing problem.	1	2	3	4	5
My swallowing problem frustrates me.	1	2	3	4	5
I get impatient dealing with my swallowing problem.	1	2	3	4	5

11. Please **circle the letter** of the one description that best describes the consistency or texture of the food you have been eating most often in the last week.

**Circle one:**

- A. Circle this one if you are eating a full normal diet, which would include a wide variety of foods, including hard to chew items like steak, carrots, bread, salad, and popcorn.
- B. Circle this one if you are eating soft, easy to chew foods like casseroles, canned fruits, and soft cooked vegetables.
- C. Circle this one if you are eating foods that are minced into small pieces and cooked until they are soft, including ground meat, mashed fruit and vegetables, very thick oatmeal, or moist rice.
- D. Circle this one if you are eating food that is put through a blender or food processor or anything that is like pudding or pureed foods.
- E. Circle this one if you take most of your nutrition by tube, but sometimes eat ice cream, pudding, applesauce, or other pleasure foods.
- F. Circle this one if you take all of your nourishment through a tube.

12. Please **circle the letter** of the one description that best describes the consistency of liquids you have been drinking most often in the last week.

**Circle one:**

- A. Circle this one if you drink liquids such as water, milk, tea, fruit juice, and coffee.
- B. Circle this one if the majority of liquids you drink are thick, like tomato juice or apricot nectar. Such thick liquids drip off your spoon in a slow steady stream when you turn it upside down.
- C. Circle this one if your liquids are moderately thick, like a thick milkshake or smoothie. Such moderately thick liquids are difficult to suck through a straw, like a very thick milkshake, or drip off your spoon slowly drop by drop when you turn it upside down, such as honey.
- D. Circle this one if your liquids are very thick, like pudding. Such very thick liquids will stick to a spoon when you turn it upside down, such as pudding.
- E. Circle this one if you did not take any liquids by mouth or if you have been limited to ice chips.

13. In general, would you say your health is:

- (circle one)
- Poor ..... 1
- Fair ..... 2
- Good ..... 3
- Very Good ..... 4
- Excellent ..... 5

### Stroke Impact Scale

These questions are about the physical problems which may have occurred as a result of your stroke.

1. In the past week, how would you rate the strength of your...	A lot of strength	Quite a bit of strength	Some strength	A little strength	No strength at all
a. Arm that was most affected by your stroke?	5	4	3	2	1
b. Grip of your hand that was most affected by your stroke?	5	4	3	2	1
c. Leg that was most affected by your stroke?	5	4	3	2	1
d. Foot/ankle that was most affected by your stroke?	5	4	3	2	1

These questions are about your memory and thinking.

2. In the past week, how difficult was it for you to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Remember things that people just told you?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in conversation.

4. In the past week, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Say the name of someone who was in front of you?	5	4	3	2	1
b. Understand what was being said to you in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialing?	5	4	3	2	1

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

3. In the past week, how often did you...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody you are close to?	5	4	3	2	1
c. Feel that you are a burden to others?	5	4	3	2	1
d. Feel that you have nothing to look forward to?	5	4	3	2	1
e. Blame yourself for mistakes that you made?	5	4	3	2	1
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following questions ask about activities you might do during a typical day.

5. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Cut your food with a knife and fork?	5	4	3	2	1
b. Dress the top part of your body?	5	4	3	2	1
c. Bathe yourself?	5	4	3	2	1
d. Clip your toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control your bladder (not have an accident)?	5	4	3	2	1
g. Control your bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1



The following questions are about your ability to be mobile, at home and in the community.

6. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Stay sitting without losing your balance?	5	4	3	2	1
b. Stay standing without losing your balance?	5	4	3	2	1
c. Walk without losing your balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

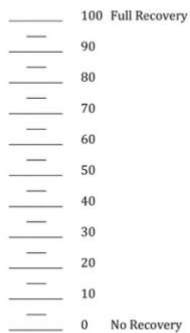
7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Carry heavy objects (e.g., bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you find purpose in life.

8. During the past 4 weeks, how much of the time have you been limited in...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Your work (paid, voluntary or other)?	5	4	3	2	1
b. Your social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. Your role as a family member and/or friend?	5	4	3	2	1
f. Your participation in spiritual or religious activities?	5	4	3	2	1
g. Your ability to control your life as you wish?	5	4	3	2	1
h. Your ability to help others?	5	4	3	2	1

### 9. Stroke Recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?



## Appendix B: Spouse Questionnaire

Thank you for your willingness to participate in this research study entitled, Taking part in this study is entirely voluntary and all responses will be kept strictly confidential. All of the paperwork should take about 30-45 minutes or less to complete. The majority of questions are multiple choice to facilitate the process for you, but in many cases you will have the opportunity to elaborate further and we will certainly appreciate any insights that you can offer us that you choose to share. We look forward to learning more about your experiences as the partner of a stroke survivor.

This survey is intended for adult partners/spouses of stroke survivors.

This study is being conducted with the University of Oregon Institutional Review Board approval. If at any time you have questions, concerns, or comments, please do not hesitate to contact Samantha Shune, Principal Investigator, at sshune@uoregon.edu or by phone at (541) 346-7494.

### Part I: Demographic and Background Information

1. What is your gender?
  - a. Male
  - b. Female
  - c. Other
2. What is your race/ethnicity? (You may select more than one)
  - a. African American
  - b. American Indian/Alaska Native
  - c. Asian
  - d. Hispanic/Latino
  - e. Native Hawaiian or Other Pacific Islander
  - f. White
  - g. Decline to Report
3. How old are you? \_\_\_\_\_ years
4. What is your current relationship status?
  - a. Married or living with a partner
  - b. Separated or divorced
  - c. Widowed
  - d. Never Married
5. What is your current employment status?
  - a. Retired
  - b. Working full-time
  - c. Working part-time
  - d. Unemployed
  - e. Other
6. Select the highest level of education you have completed.
  - a. No schooling completed
  - b. Completed 8<sup>th</sup> grade
  - c. High school graduate (high school diploma or equivalent)
  - d. Certificate or diploma beyond high school level
  - e. Bachelor's degree
  - f. Master's, professional, or doctoral degree
7. What was the date of your partner's most recent stroke (month/date/year)?
8. Did your neurologist or family doctor provide any information about the changes you might expect as a result of your partner's stroke?
  - a. Yes
  - b. No
9. Were you given information on stroke prevention or warning signs of a stroke by a physician or other medical professional?
  - a. Yes
  - b. No
10. Does your partner require the help of another person with any of the following personal care needs?
 

	Yes	No
Eating		
Bathing		
Dressing		
Getting around inside the home		
11. Does your partner have problems with chewing or swallowing that cause difficulty when they eat?
  - a. Yes
  - b. No
 If **yes**, please describe.
12. Have you ever participated in a stroke support group?
  - a. Yes
  - b. No

### Part II: Relationship-Related Questions

For each of the following statements, please indicate the extent to which you agree or disagree. Consider how you are currently **feeling** at this moment in time. The phrase "the stroke" will be used to represent your partner's most recent stroke.

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
Since my partner's stroke, I feel isolated.						
Since my partner's stroke, I feel depressed.						
Since my partner's stroke, I do not feel like my typical self.						
The stroke has negatively impacted my relationship with my <b>partner/significant other</b> .						
The stroke has negatively impacted my relationship with other <b>immediate family members</b> .						
The stroke has negatively impacted my relationship with <b>my friends and/or my involvement in the community</b> .						
I feel as close to my partner as I did before their stroke.						
I am able to show my partner as much care/affection as I did before their stroke.						
I can talk as directly and openly with my partner as I did before their stroke.						

1. Has your family's overall mood changed since your partner's stroke?
  - a. Yes
  - b. No
 If yes, how?

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
I involve my partner in discussions about his/her care as related to their stroke.						
I feel comfortable talking about the stroke with my partner.						
I feel comfortable sharing feelings related to the stroke with my partner.						
My partner's stroke has negatively impacted my participation in joint activities with my partner.						
I feel supported by my family and/or friends.						
I have taken on more roles in the family since my partner's stroke.						

2. What are the current strengths of your relationship with your partner/significant other?

3. In what ways could your relationship be made stronger?

4. Have your household responsibilities changed since your partner's stroke?
  - a. Yes
  - b. No

If yes, what things do you do now that you did not do before?

**Part III: Mealtime-Related Questions**

For each of the following statements, please indicate the extent to which you agree or disagree. Consider how you are currently feeling at this moment in time. If a statement does not appear to apply to you, indicate "N/A".

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree	N/A
My partner enjoys eating.							
I enjoy eating with my partner.							
I enjoy eating out (e.g., at restaurants, with friends) with my partner.							
My partner enjoys eating meals with me.							
My partner eats with our family as often as he/she did prior to his/her stroke.							
My partner appears to be embarrassed to eat in front of others.							
It is easy to find foods appropriate for my partner's diet (e.g., modified food textures, thickened liquids) <b>at home</b> .							
It is easy to find foods appropriate for my partner's diet (e.g., modified food textures, thickened liquids) <b>outside of the home</b> .							
I feel like I "nag" my partner during meals.							
I am afraid my partner will choke during meals.							
I know what to do if my partner chokes during a meal.							
I socialize with my partner during mealtimes as frequently as I did prior to his/her stroke.							

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree	N/A
It takes my partner longer to complete meals than everyone else.							
It has been harder than expected to manage mealtimes since my partner's stroke.							
It takes more time to prepare food for meals than it did prior to my partner's stroke.							
Preparing a modified diet and/or thickened liquids is stressful.							
I feel that I am successful in preparing healthy, enjoyable foods for my partner.							
I am confident in my ability to prepare an appropriate meal for my partner.							
I avoid eating particular foods because my partner cannot eat them.							
My partner's needs during meals interfere with my own eating/eating experience.							
I understand why eating a modified diet and/or drinking thickened liquids is important for my partner.							
Mealtime-/eating-related costs have increased since my partner's stroke.							
My mealtime-/eating-related roles have changed since my partner's stroke.							

1. Who prepares most of the meals in your household?

- Self
- Partner/significant other
- Child
- Other family caregiver
- Hired help
- Other

2. Who prepared the meals in your household prior to your partner's stroke?

- Self
- Partner/significant other
- Child
- Caregiver
- Other hired help
- Other

3. Has your partner been given a diagnosis of dysphagia or swallowing problems?

- Yes
- No (if no, continue with question 4).

If **yes**:

i. Is it difficult to modify foods/liquids to the correct consistency at home?

- Yes
- No

If **yes**, please explain.

ii. How much additional time, on average, does it take to prepare your partner's meals?

- It doesn't take any extra time to prepare my meals.
- 1-15 min
- 16-30 min
- 31-45 min
- 46 min or more

iii. Were you given any information on dysphagia (swallowing problems) or dysphagia diets prior to leaving the hospital?

- Yes
- No

If **yes**, who gave you this information?

- Doctor
- Speech-language pathologist
- Dietician
- Nurse
- Other health professional

iv. Do you feel like you were given enough information prior to leaving the hospital on preparing meals safely at home?

- Yes
- No

v. Do you and your partner follow the recommendations and guidelines that your speech-language pathologist or physician gave you?

- Yes
- No

If **no**, why do you not follow the recommendations (select all that apply)?

- Too difficult.
- It would take too much time.
- I did not understand the recommendations.
- My partner does not think s/he has any problems swallowing.
- Other (please specify): \_\_\_\_\_

4. Other than swallowing, does your partner have any problems that impact eating or mealtimes? Please select all that apply.

- Difficulty feeding him/herself
- Dentures don't fit
- No dentures
- Missing teeth
- Get tired easily
- Other (please specify): \_\_\_\_\_

***Part IV: Conclusion***

Please feel free to include any additional comments, questions, or concerns regarding stroke, mealtimes, eating/swallowing impairments, relationships, or this study in the space below. We greatly appreciate your time and effort. Your opinions and comments are very important to us.

**Appendix C: IDDSI-FDS Table**

FOOD LEVELS							
7	6	5	4	3	N/A (no food)		
3	2	1	N/A	N/A	0	N/A (no drinks)	DRINK LEVELS
4	3	2	1	N/A	N/A	4	
5	4	3	2	1	N/A	3	
6	5	4	3	2	1	2	
7	6	5	4	3	2	1	
8	7	6	5	4	3	0	

From: Steele, C. M. et al. (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.

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