

THE PSYCHOSOCIAL IMPACT OF POST-STROKE  
DYSPHAGIA ON THE FAMILIAL DYAD

by

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A THESIS

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Approximately 39 to 81% of stroke survivors experience dysphagia or swallowing difficulties (Khedr et al., 2021). Post-stroke dysphagia can have a lasting effect on the quality of life of both the stroke survivor and their informal caregiver. The purpose of the current study was to investigate the psychosocial impact of post-stroke dysphagia on the family dyad. Individual and dyadic semi-structured interviews were conducted. Throughout the data collection and transcription processes, the research team engaged in memo writing. The memos and transcripts were analyzed as primary sources of data in the qualitative study.

Results revealed a perceived loss of autonomy and independence, the presence of family and friend support systems, a lack of support from healthcare professionals, and the toll of post-stroke dysphagia and the stroke recovery process on the dyad's mental health. These findings suggest the importance of providing individualized medical and psychological support for both members of the dyad, including the uncompensated family caregiver who has now altered their lived experiences to better support the survivor.

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## **Introduction**

### **Definition of Dysphagia**

Dysphagia is a term used to describe swallowing difficulties which occur when an individual has challenges with the transportation of saliva, food, liquid and/or medicine from the mouth to the stomach (Helldén et al., 2018). The process of swallowing involves three main stages. The first stage, the oral stage, includes the formation of the bolus, a mass made of food and saliva, via chewing. After the bolus' formation, it is then transported to the pharynx. Next, during the pharyngeal stage, the bolus is moved through the pharynx to the esophagus while maintaining airway protection. Lastly, during the esophageal phase, the bolus is moved through the esophagus to the stomach (Panara et al., 2021). Any disturbance during the process of swallowing classifies as dysphagia (Sura et al., 2012).

The incidence of dysphagia is relatively high. In the United States alone, approximately 1 in 25 adults experience swallowing difficulties annually (Bhattacharyya, 2014). However, the prevalence of dysphagia fluctuates across many conditions and age groups, causing the true number of affected individuals to often be underestimated (American Speech-Language-Hearing Association; Groher & Crary, 2016). Predictors of dysphagia include, but are not limited to, increased frailty and age, poor oral health, having a current or former history of smoking, and being female (Wilkins et al., 2007; Namasivayam-MacDonald et al., 2022). Dysphagia is a symptom of an underlying disease or medical condition. Conditions commonly associated with dysphagia include stroke, traumatic brain injury, dementia, cerebral palsy, Parkinsonism, and iatrogenic diagnoses (Groher & Crary, 2016).



While dysphagia is not a permanent disorder for all individuals, some experience the symptoms and consequences of dysphagia for the rest of their lives (Helldén et al., 2018). Symptoms of dysphagia include, but are not limited to, difficulty controlling one's food or saliva, difficulty recognizing food, and coughing and/or choking prior, during, or after mealtimes. Consequences of dysphagia include pneumonia, dehydration, malnutrition, and an increased mortality rate. Pneumonia is defined as the "aspiration of swallowed materials from the pharynx that results in a lung infection" (Groher & Crary, 2016, p. 369). If an individual has aspiration pneumonia, they are more likely to have poor nutrition during the longer hospital stay and greater disability in the following months. Dehydration and malnutrition may lead to decreased mental clarity and energy, and if severe, could lead to organ failure or a compromised immune system. Individuals with dysphagia are also at risk of emotional and social consequences including fear, anxiety, depression, and fewer social interactions (Groher & Crary, 2016). As social interactions often revolve around food, when one's ability to swallow is impeded, eating food may turn into a mere nutritional necessity rather than an enjoyable pastime (Groher & Crary, 2016; Mirams, 2022).

### **Post-Stroke Dysphagia**

Since the 1990s, the prevalence of stroke has increased by 68% due to an escalation in stress, poor health and lifestyle choices, economic uncertainty, and urbanization (Bai Shu et al., 2019). A total of 16.9 million individuals, including 700,000 Americans, experience a stroke each year (Béjot et al., 2015; Daniels & Huckabee, 2014).

A stroke's damage to the brainstem, cortex, muscles, or nerves involved in swallowing can lead to dysphagia (Shaker & Geenen, 2011). Unfortunately, post-stroke dysphagia is common with the incidence of swallowing difficulty following a stroke estimated to range from 39% to 81% (Khedr et al., 2021). This wide range of incidence can be attributed to a variety of factors: the study's methods of selecting participants and evaluating data, its definition of dysphagia, and the time duration after the stroke (Daniels & Huckabee, 2014). Other risk factors may also increase the incidence of stroke in certain populations. For example, research has found that Asians and other minority groups have a higher adjusted odds ratio for post-stroke dysphagia when compared to Caucasians (Bussell & González-Fernández, 2011). Regardless of these differences, a substantial number of stroke survivors will experience dysphagia each year.

### **Caregiver Burden**

Caregiver burden is defined as “the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time” (Liu et al., 2020, p. 438). After a stroke, roughly half of stroke survivors require informal care from family members (Robinson et al., 2022). When stroke survivors are discharged from the hospital into their family's care, both parties may have trouble returning to their pre-stroke lives (Farahani et al., 2020). The post-stroke recovery process can take an emotional and physical toll on the caregiver in addition to the survivor. A longitudinal study revealed that informal caregivers who experienced the strain of caregiver burden had a mortality rate that was 63% higher than the control group who were not caregivers (Schulz & Beach, 1999).

Informal caregivers and post-stroke survivors often have to alter their daily lives, which may have a negative impact on the dyad. Caregivers frequently have to accommodate to a range of requirements and needs of the post-stroke survivor; the responsibility of a caregiver can be equal to or greater than the stress associated with a full-time job (Losada et al., 2009). Duties of a caregiver can include, but are not limited to, feeding, cleaning, and cooking (Li et al., 2021). Since a caregiver must often adapt to the requirements and needs of the stroke survivor, the ability for the caregiver to live a life full of leisure and pleasure may be reduced. If the informal caregiver does not participate in events or activities that brings them joy, depression and social isolation can occur, leading the caregiver to be more susceptible to developing mental disorders (Losada et al., 2009). Emotional burden is more likely to occur in caregivers of loved ones with dysphagia. A previous study revealed that dysphagia was an independent predictor of increased emotional caregiver burden, even when accounting for other factors known to increase burden (Shune & Namasivayam-MacDonald, 2020). Furthermore, 70% of the caregivers who had partners with dysphagia identified their emotional burden as moderate to severe (Shune & Namasivayam-MacDonald, 2020).

A recent study involving a small number of family caregivers of individuals with post-stroke dysphagia and other comorbidities identified a number of interrelated practical, social, and emotional changes in their daily lives (Robinson et al., 2022). The study's caregivers noted changes to their lifestyle and daily roles/responsibilities, while feeling increased worry and guilt. They also noted feeling entirely responsible for managing the dysphagia on their own, being their loved one's "only means of survival" (Robinson et al., 2022, p.7).

## **Theory of Dyadic Illness Management**

The Theory of Dyadic Illness Management centers around the idea that the management of an illness involves two people, the caregiver and the care recipient. The health and wellbeing of this dyad are the crucial targets for intervention (Lyons & Lee, 2018). Past research on illness management, such as the Robinson et al. (2022) article on post-stroke dysphagia, has often focused on the patient or the informal caregiver independently, but rarely has focused on the dyad as a unit. However, the wellbeing and physical health of the caregiver and stroke survivor are interdependent. As seen in Figure 1 (below), when the emotional, financial, and physical difficulties of the caregiver rise due to his or her new responsibilities, the health of both the caregiver and care recipient can decline (Shune & Namasivayam-MacDonald, 2020). Thus, it is important to better understand each person's independent perceptions of the illness' impact, but also understand the shared perspective of managing the dysphagia as a dyadic unit.

## **Purpose of the Current Study**

Caregiver burden is a pressing health priority, particularly following a stroke. The presence of dysphagia can increase the burden of care within these families. However, research on the impact of post-stroke dysphagia across the familial dyad is sparse. The aim of this study was to examine the reciprocal relationship between post-stroke dysphagia and the dynamics within the familial dyad.

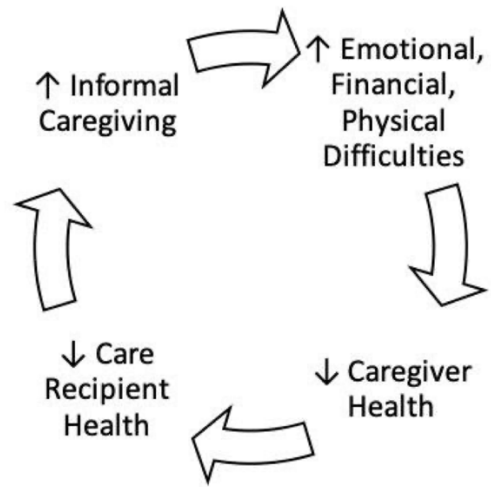


Figure 1: The cyclical model of the interdependent relationship between caregiver and care recipient from Shune & Namasivayam-MacDonald (2020).

## **Methods**

### **Participants**

Stroke survivors and their informal (non-compensated) caregivers were recruited as potential study participants. Information about study participation was dispersed via IRB-approved flyers and emails. The flyers were disseminated throughout the Eugene and Portland, Oregon communities, including medical sites and other public locations (e.g., libraries). Additionally, details about the study were posted on Craigslist, Nextdoor.com, and the ResearchMatch recruitment website. Emails were sent to local speech-language pathologists in the Eugene and Portland communities to share with their patients. If potential participants were interested in partaking in the study, they were instructed to contact the research team via telephone or email. After potential participants notified the research team of their interest, a brief screening process occurred to determine the potential participants' eligibility. Each eligible participant received \$40 as compensation for completion of the study.

### **Inclusion and Exclusion Criteria**

Participant eligibility criteria purposely remained broad in an effort to capture an array of experiences and to maximize the variability of results. To meet the inclusion criteria, stroke survivors had to be medically stable, be without a prior medical diagnosis of dysphagia before their most recent stroke, live with a family member, and have the language and cognitive capabilities to partake in an interview process. Inclusion criteria for caregiver participants required eligible individuals to be without a recent diagnosis of an acute or chronic illness (i.e., from the time of the survivor's most

recent stroke) in order to avoid confounding results. Each individual in the dyad had to meet their respective eligibility criteria for inclusion in the study.

### **Data Collection**

All study procedures were approved by the Institutional Review Board at the University of Oregon. Data were collected by the principal researcher and a research assistant; both were licensed and certified speech-language pathologists. The principal researcher served as a doctoral-level faculty member at the University of Oregon and the research assistant was a University of Oregon PhD student. At the time of data collection, the principal researcher had over twelve years of experience as a speech language pathologist and had worked in dysphagia management across healthcare settings (e.g., skilled nursing and long-term care facilities). The research assistant had eight years of experience as a speech-language pathologist in hospitals and outpatient clinics.

All participants went through a series of semi-structured interviews conducted by the principal researcher. A portion of one interview was conducted by the research assistant due to a scheduling conflict. During the interview process, the principal researcher or research assistant asked several broad questions to generate discussion about the participants' lived experiences regarding the stroke and related dysphagia (see Appendix A for the complete interview guide). When applicable, every dyad was interviewed together in addition to each member being interviewed separately. In doing so, the perceived impact of dysphagia on daily life and the family dynamic was more accurately depicted.

The interviews with both the dyad and individuals lasted between 8 and 82 minutes. Interviews were conducted either in person or virtually via Zoom, based on participant preference. If the participants elected to undergo the interview process in person, they chose if the interview was conducted at their home or at the Optimizing Swallowing and Eating for the Elderly Laboratory (O-SEE) on the University of Oregon campus. For all options, only the interviewer and participants were present. The entire interview process was recorded for later transcription via the O-SEE research assistants or the Rev Transcription Service. Research assistants transcribed all audible sounds or gestures and indicated when there were unintelligible utterances. To ensure reliability, all transcriptions were checked by another research assistant. Any discrepancies were discussed among the research assistants to increase transcription accuracy.

While their family member was being interviewed, the other participant completed a set of questionnaires. The stroke survivor completed three forms. The first survey questioned the participant on their relationship with their family member(s), their mealtime experiences, and general background and demographic information. Next, the survivor completed the Stroke Impact Scale (SIS) questionnaire which solicited responses from the participant regarding the functional impacts of their stroke (Duncan et al., 1999). Lastly, the stroke survivor completed the Swallowing-Related Quality of Life (SWAL-QOL) Survey (McHorney et al., 2002). The SWAL-QOL is a tool that aims to discover how swallowing difficulties affect the individual's everyday quality of life. The caregiver solely completed the first survey, which included questions on the demographic and background information of the caregiver, relationship-related questions, and mealtime-related questions.



## **Data Analysis**

Data were analyzed by three research assistants and the principal investigator of the O-SEE laboratory. Throughout the data collection and transcription process, the research team engaged in memo writing, in which the team members wrote down their thoughts in order to capture potential theoretical connections or ideas that needed more exploration. The memos provided preliminary information and insight on potential themes. The memos and the transcriptions were analyzed as primary sources of data. All data were analyzed following an inductive thematic analysis procedure, including data familiarization, thematic code generation, and thematic building (Braun & Clarke, 2006). During data familiarization, the team completed initial readings and re-readings of the transcripts and memos, noting potential codes and their patterns of occurrence. During the coding process, each transcription and memo were reanalyzed line by line to find and create a set of thematic categories across the transcripts and memos. As data were continually collected and analyzed, new concepts were documented, and codes were connected mid-data analysis. The new concepts were either added to a pre-existing category as sub-themes or formed a new thematic category.

Each transcription was read and coded by at least two team members. Research assistants received the same training regarding the coding process and weekly debriefs were held to discuss any questions, thoughts, or discrepancies. Similar to the transcription revision process, differences in research assistants' perceptions of coding categories or subthemes on the same transcription were discussed. Open conversation encouraged joint interpretation of data. During the process of data analysis, the team of research assistants also pulled quotations that best exemplified the established

categories and subthemes. Quotations, notes, and memos regarding the transcriptions for future data analysis were not kept in one location or database but instead memos were individually stored by the research assistants.

## Results

### Participants

Fifteen participants met the eligibility criteria and were recruited for participation in the study. Of the fifteen individuals, there were seven stroke survivor-caregiver dyads and one individual caregiver. The seven survivor-caregiver dyads were comprised of one parent-child dyad and six spousal dyads. The stroke survivors primarily identified as male (71.4%) and all were White and non-Hispanic, with a mean age of 67.9 years (SD = 10.5; range of 59-88). The caregivers primarily identified as female (75.0%) and were all White and non-Hispanic, with a mean age of 62.8 years (SD = 12.7; range of 39-86). See Tables 1 and 2 for full demographic and background information on the stroke survivors and caregivers, respectively.

Table 1. Demographic and Background Information of the Stroke Survivors

|                    | Age      | Gender | Race and Ethnicity  | Relationship to Caregiver | Stroke (year) | SWAL-QOL | SIS  |
|--------------------|----------|--------|---------------------|---------------------------|---------------|----------|--|
| <b>Survivor #1</b> | 88 years | Male   | White, non-Hispanic | Spouse                    | 2011          | 70.48    | Physical: 61.60<br>Cognitive: 62.50<br>Emotional: 72.20<br>Social: 37.50 |
| <b>Survivor #2</b> | 70 years | Male   | White, non-Hispanic | Father                    | 2017          | 59.32    | Physical: 31.25<br>Cognitive: 50.00<br>Emotional: 55.56<br>Social: 59.38 |
| <b>Survivor #3</b> | 62 years | Male   | White, non-Hispanic | Spouse                    | 2016          | 63.86    | Physical: 58.04<br>Cognitive: 78.57<br>Emotional: 77.78<br>Social: 59.38 |
| <b>Survivor #4</b> | 59 years | Female | White, non-Hispanic | Spouse                    | 2006          | 79.12    | Physical: 52.68<br>Cognitive: 57.14<br>Emotional: 86.11<br>Social: 62.50 |
| <b>Survivor #6</b> | 74 years | Male   | White, non-Hispanic | Spouse                    | 2015          | 62.08    | Physical: 43.75<br>Cognitive: 46.43<br>Emotional: 66.67<br>Social: 34.38 |
| <b>Survivor #7</b> | 60 years | Female | White, non-Hispanic | Spouse                    | 2016          | 36.50    | Physical: 37.50<br>Cognitive: 44.64<br>Emotional: 38.89<br>Social: 12.50 |
| <b>Survivor #8</b> | 62 years | Male   | White, non-Hispanic | Spouse                    | 2016          | 81.38    | Physical: 76.79<br>Cognitive: 71.43<br>Emotional: 75.00<br>Social: 46.88 |

*Note.* Survivor #5 was deceased and therefore was not a participant in the study

Table 2. Demographic and Background Information of the Caregivers

|                     | <b>Age</b> | <b>Gender</b> | <b>Race &amp; Ethnicity</b> | <b>Relationship to Survivor</b> |
|---------------------|------------|---------------|-----------------------------|---------------------------------|
| <b>Caregiver #1</b> | 86 years   | Female        | White, non-Hispanic         | Spouse                          |
| <b>Caregiver #2</b> | 39 years   | Female        | White, non-Hispanic         | Daughter                        |
| <b>Caregiver #3</b> | 60 years   | Female        | White, non-Hispanic         | Spouse                          |
| <b>Caregiver #4</b> | 61 years   | Male          | White, non-Hispanic         | Spouse                          |
| <b>Caregiver #5</b> | 65 years   | Female        | White, non-Hispanic         | Widow                           |
| <b>Caregiver #6</b> | 64 years   | Female        | White, non-Hispanic         | Spouse                          |
| <b>Caregiver #7</b> | 64 years   | Male          | White, non-Hispanic         | Spouse                          |
| <b>Caregiver #8</b> | 63 years   | Female        | White, non-Hispanic         | Spouse                          |

## Themes

Three overarching themes were present across the data: 1) Loss of autonomy and independence; 2) Support systems and lack of support from healthcare professionals; and 3) Toll of post-stroke dysphagia and stroke recovery on mental health. Each of these themes will be further described below, using the participants' own words for thematic illustration.

### *Theme 1: Loss of Autonomy and Independence*

A loss of autonomy was reported by stroke survivors during the interview process. A number of participants disclosed that symptoms of their dysphagia and stroke barred them from completing daily tasks and everyday chores. Even processes that used to be entirely automatic and without thought, such as swallowing, proved to be a challenge. One survivor reported having to consciously think about swallowing during eating and drinking after their stroke despite, "learn[ing] how to swallow when [I] was little" (Stroke Survivor #2). Another survivor reminisced on his former abilities to complete even basic tasks:

When I started to really experience the swallowing difficulties, it concerned me that there's so many things that I used to take for granted. I didn't ever think about how many times I needed my left hand to do something, open a jar or...hold on to something while I was doing another thing with my right hand. (Stroke Survivor #3)

Executing other former responsibilities, such as driving, mowing the lawn, cooking, emptying the dishwasher, and handling money were also no longer plausible. In order to maintain the household, the caregiver would often assume the survivor's former responsibilities and complete the tasks. Thus, an added workload was placed upon the

caregiver. This increased burden and change in responsibility was expressed by several participants, including both the survivors and caregivers, such as:

...before the stroke I would cook a lot. I was a little bit of a fanatic of how the lawn looks and cleaning house. I would help clean the house. I'm not really doing any of those things anymore so not only is [my wife] my caregiver, but she has taken on the role of doing all those other things. (Stroke Survivor #3)

There's a lot of things that he used to do that he doesn't do anymore. I've picked up a lot of it. That's what I think is one of the worst parts. (Caregiver #1)

In addition to the added responsibility of completing new daily chores, some caregivers felt the need to “mother hen” their loved ones to ensure their needs were being met. They assumed “an overly protective maternal attitude” (Merriam-Webster). An example of a mother hen caregiving approach in the context of managing the post-stroke dysphagia was described by Caregiver #3:

If we're having chicken or steak or something for dinner that he can't just bite into, I have to cut his food for him, and I have to cut it into, I try to cut it into bite sized pieces, because he would take a whole chunk of steak and stick it in his mouth and try and chew it and swallow it. I think about it and sometimes I do it in the kitchen before I sit down with him, because I sort of feel like when my kids were little and I would have to cut their food for them.

This mother hen mentality was frustrating to some of their loved ones, as expressed by Stroke Survivor #6, “...I know she's looking after my wellbeing but there are times that I just want to scream because she mother hens me so much.” Despite this frustration at times, the stroke survivors who experienced a mother hen caregiving style acknowledged that their caregivers' intentions were pure and came from a place of love. For example,

[My sons] were almost like smothering me and I didn't want to say anything because I knew their intentions were good, but they were "here I'll do this for you," "you don't," "don't," "we don't," you know, "don't," you know and this and that and they overly protective I think a lot of people may be, cause it scared them almost losing someone.  
(Stroke Survivor #8)

For the stroke survivors, an inability to complete hobbies or activities that they once regularly enjoyed was discussed in addition to a loss of autonomy. Activities like golfing, browsing one's computer, walking around the neighborhood, and burning songs onto compact discs proved to be too difficult or painful. The caregivers similarly noticed these changes. As Caregiver #1 described about her husband:

[He] used to do a lot on his computer, spent a lot time on his computer. He was like gospel music and lots of boxes of these LPs that he collected. He was putting those on CDs. That just fully stopped. He didn't remember how to do any of that anymore. He couldn't even turn the computer on.

### *Theme 2: Support Systems and Lack of Support from Healthcare Professionals*

Both caregivers and stroke survivors reported receiving emotional and resource support from family members and friends. Emotional support is defined as "the verbal and nonverbal processes by which one communicates care and concern for another, offering reassurance, empathy, comfort, and acceptance" (APA Dictionary of Psychology). For many caregivers, time with family and friends provided an opportunity for open conversation about their added caregiver responsibilities and increased comfortability in their new role. Such support was viewed as extremely valuable. As a number of caregivers reported:



If you don't have family or friends or someone that you can really lean on, even if it's just your church, you know... it makes it that much more difficult to get through. (Caregiver #2)

My sister Alice, can call her up anytime and say anything I want and have an empathetic ear. (Caregiver #7)

...it was good to have the family there because you're not relying just on yourself to take it all in and figure it all out... I was taking over his care and it scared me. It really scared me because I was put in a position that I really wasn't comfortable at all with (Caregiver #8)

Resource support, in the context of this study, can be defined as the processes, both verbal and nonverbal, which connect an individual to materials, measures and methods to better aid the dyad in the process of post-stroke and dysphagia recovery. According to several stroke survivors, resource support from friends and family provided the dyad with recovery guidance and allowed for a better management of both stroke and dysphagia symptoms. This, in turn, helped minimize the caregiver's stress. For example:

The doctors never told us anything about [the "cure" for choking], but we have a friend that lives over at the coast. He says 'when you start choking lift your arms up above your head.' (Stroke Survivor #6)

...I had a really good friend who was an ICU nurse. The ICU nurse where he was in the hospital at [facility name]. She's the one that would give me the answers that I was seeking. (Caregiver #5)

Unfortunately, not all study participants were provided with the same aforementioned emotional or resource support. Several participants described fluctuating levels of support from family. One caregiver stated her siblings did not support her decisions regarding traveling with their father post-stroke (Caregiver #2).

Another caregiver stated that because of his personal diagnosis of autism spectrum disorder (ASD), there was a lack of support from his extended family in his daily life. However, when his wife experienced her stroke, support from the extended family appeared to increase, at least during the most acute stages of her recovery:

Well, some family members have been ... have completely distorted what's going on, and so for a while, it almost looked like [wife's] stroke was improving the relationship with the family. There was some concern, and, you know, "What can we do?" (Caregiver #4)

While a majority of the dyads reported receiving positive support from family members and friends, a lack of support from healthcare professionals was expressed. Multiple participants described how medical staff failed to provide their families with individualized guidance after the stroke, particularly regarding dysphagia management.

Caregiver #5 recalled her experience:

I was basically given a sheet of paper, this is what you can have, this is what you should do. It's there. It's knowledge, but it did not fit, you know?....And so I can't say that I tried super hard to follow [the suggestions], but it was kind of like I did try and and- and it just didn't seem to fit, so I went with what worked for me and what worked for [the stroke survivor].

Misinformation from medical staff was another frustration expressed by participants as the participants wanted to be able to rely on medical predictions. Two participants reported this frustration when provided with inaccurate predictions of the stroke survivors' full recovery:

They told me when I was in the hospital, they said, 'oh yeah, within a year you'll never even know anything happened. See, you just had a real mild, light [stroke], nothing to worry about.' Well, it's been five years and I still fight with it. (Stroke Survivor #6)

[The doctor] says you're probably looking at five years for this type of brain injury that [the stroke survivor] has had, and you know just kind of where he's at and so that's initially what I kind of based the care on, and you know hindsight we're way off on that...it wasn't five years, it was twenty... (Caregiver #5)

A lack of information from healthcare professionals was also indicated. One participant shared that his speech pathologist never officially diagnosed or informed him that he had dysphagia. This participant expressed, "I don't think I ever heard the word [dysphagia] until we started this interview" (Stroke Survivor #3). Another stroke survivor stated he was not provided with exercises post-stroke to aid in the recovery process.

### *Theme 3: Toll of Post-Stroke Dysphagia and Stroke Recovery on Mental Health*

Stroke survivors revealed that the symptoms and consequences of post-stroke dysphagia and the stroke recovery process took a negative toll on their overall mental health and wellbeing:

I feel so lousy all the time. I don't know what's going on most of the time. (Stroke Survivor #1)

I've been having some depression issues and I think the main factor in the depression that I'm feeling in my mental picture of myself is that I'm damaged. I'm not whole somehow. It's just really hard for me to deal with (Stroke Survivor #3)

Additionally, particularly related to dysphagia, caregivers reported anxiety and fear surrounding the possibility of their loved ones choking during their absence. As one spousal caregiver reported:

It scares me a lot, actually. I think more than you [husband] know it does. I mean, I do worry about him choking on food when I'm not there.

He chokes a lot, and I don't think he realizes that was why I was so interested in coming into this study, because I don't think he realizes how often he does it. (Caregiver #3)

However, the caregivers' anxieties and fears surrounding choking were not always shared by the stroke survivors. Discrepancies in the reported consequences of the dysphagia and stroke, or appraisal of the conditions, between the caregiver and stroke survivor were present in several transcriptions. For example, when asked how his swallowing has impacted his life, Stroke Survivor #3 indicated that, "I don't think it's impacted, except that maybe scaring you [wife] a little bit." Conversely, his wife reported being highly fearful of him choking, worrying about whether she will be "strong enough to give him the Heimlich maneuver" and stated that it occurs often without him recognizing it, as noted in her quote above. While he appeared to be less aware of the discrepancy in their appraisal, she reported that her husband:

... said, 'I haven't choked in a while.' He has and he does, and I think his therapist did make the recommendation about drinking, eating, drinking and eating, but again, the big issue is that he doesn't remember to do that. (Caregiver #3)

In order to navigate through the stress of the stroke recovery process, both caregivers and stroke survivors reported using a variety of coping mechanisms, many of which were unhealthy options.

It is hard, and I struggle with my weight, that's my way of self-medicating myself and I've gained a lot of weight in the last two years taking care of him, because I'm not always practicing good self-care. (Caregiver #3)

...in my wisdom and my addictive brain, I started using marijuana as a pain reliever. And a sort of an anxiety, a treatment for anxiety. And I found that it worked for both of those things. However, I don't have a

medical marijuana card, and it wasn't long before I wasn't using it medicinally. I was just using. (Stroke Survivor #3)

In recognition of the impact of stroke and dysphagia on their mental wellbeing, some participants suggested the importance of therapy. According to one caregiver, “therapy needs to be a must for all family members” (Caregiver #5). Another dyad disclosed attending couples therapy to manage their mental health.

## **Discussion**

While previous studies have investigated the impact of post-stroke dysphagia on the survivor and caregiver individually, the joint effect of post-stroke dysphagia on the dyad as a unit has been vastly overlooked. This study aimed to examine the relationship between post-stroke dysphagia and the inner workings of the familial, dyadic relationship. Data analysis revealed that participants encountered a broad range of experiences, which included some that were shared between the survivors and caregivers and others that were unique to the different members of the dyad. From this broad range of experiences, three main themes were formed: 1) Loss of autonomy and independence; 2) Support systems and lack of support from healthcare professionals; and 3) Toll of post-stroke dysphagia and stroke recovery on mental health.

### **Loss of Autonomy and Independence**

Results from our study revealed that a loss of autonomy and independence were felt by both stroke survivors and caregivers. A recent study, conducted by Nagamine et al. (2021) investigated the potential association between poor oral function and loss of independence in functionally independent adults. The study's results suggested that participants with poor oral function and a dysphagia-related quality of life impairment were at a higher risk of developing a loss of independence in comparison to participants without poor oral function. In our study, a loss of independence and autonomy for stroke survivors lead to a lack of participation in household chores and activities that were once regularly enjoyed. Li et al.'s (2021) qualitative meta-analysis corroborated the findings of the current study; patients with post-stroke dysphagia had a limited functional ability to complete daily chores and tasks. Several stroke survivor

participants in our study expressed frustration and loss at their lack of autonomy. These findings echoed the results of Hughes and Cummings' (2020) study which investigated potential grief and loss in stroke survivors and their caregivers. The study found that patient loss revolved around the physical changes that occurred after the stroke and the repercussions it had on their ability to participate in hobbies, events, and other activities of daily living. However, unlike Hughes and Cummings' study, Li et al.'s meta-analysis revealed that several stroke survivors enjoyed the lack of autonomy and were glad to be relieved of their former household responsibilities (2021).

According to our findings, the added responsibility of completing the survivor's former daily chores usually fell to the caregiver. Said findings are in agreement with Li et al.'s (2021) qualitative meta-analysis which found that caregivers adopted the responsibility of the housework. The added workload was not always appreciated and was described as one of the "worst parts" of post-stroke dysphagia and stroke recovery in our study. These findings align with results from a recent study which explored the family experience of caring for a spouse with post-stroke dysphagia; the management of dysphagia without additional support created responsibility that the caregivers were not always happy to take on (Robinson et al., 2021). Findings from Namasivayam-MacDonald and Shune's (2018) systematic review also revealed that caregivers of individuals with dysphagia experience drastic changes in their daily routines as these routines became more centered around the care recipient receiving proper nutrition, such as regimented tube feeding protocols. Data analysis in the current study revealed that previously automatic and unconscious actions, like swallowing, were no longer

easy for all stroke survivors, as they now had to be consciously thought about before being fulfilled.

### **Support Systems and Lack of Support from Healthcare Professionals**

Findings from the present study revealed that many participants experienced positive emotional and resource support from friends and family. Caregivers expressed that they were able to rely on both religious institutions and family/friends. According to Northcott et al. (2015), a study which explored factors associated with social support post-stroke, friendships were more likely to be maintained if they were made in consistent, supportive groups like churches. Stroke survivors and caregivers from our study reported that support from family members and friends allowed for better recovery guidance and management of both stroke and dysphagia symptoms. Similar findings were observed in a research study that examined the impact of social support on first-time stroke survivors; the level of perceived social support was a significant predictor of change in a stroke survivor's functional status (Glass et al., 1993). Higher levels of social support, which included emotional exchanges, were found to be predictive of a quicker recovery rate and a greater level of functioning (Glass et al., 1993). However, other literature on post-stroke dysphagia has been incongruent with the findings from our study about the presence of family/friend support. For example, Robinson and colleagues (2022) investigated the experience of spouses living with a significant other diagnosed with post-stroke dysphagia. Their informal caregivers described feeling left to their own devices and like they were solely responsible for their family member.



In addition to discussing the presence and positive effects of social support, the participants in the current study also discussed a lack of support from their healthcare providers. Provided support from medical staff was not individualized to the needs of the family and stroke survivor; therefore, the medical advice was not realistic for several of the dyads. Participants in the current study would alter given medical advice or not follow said advice in order to better support the individualized needs of the stroke survivor. These findings are in agreement with Robinson et al.'s (2022) study which revealed that informal caregivers reported “bend[ing] the rules” of advice given by medical professionals.

### **Toll of Post-Stroke Dysphagia and Stroke Recovery on Mental Health**

In the current study, participants revealed that post-stroke dysphagia and the added role of becoming a caregiver took a negative toll on their mental health. Caregivers reported anxiety at the possibility of their loved ones choking in their absence. Previous literature has echoed said findings; one study revealed that caregivers reported an increase in the fear and anxiety related to choking, their overall caregiver responsibilities, and the nutritional status of their loved one (Namasivayam-MacDonald & Shune, 2018). Our study's results uncovered the presence of discrepancies in opinion between the caregiver and care recipient, particularly regarding the appraisal of post-stroke dysphagia's symptoms. Past research on the presence of incongruence between care recipient and caregiver revealed that discrepancies may have a negative effect on the dyad's ability to manage the illness and work together (Lyons & Lee, 2018). Additionally, according to the Dyadic Theory of Illness Management, this incongruence in appraisal can lead to poorer dyadic health and wellbeing (Lyons & Lee, 2018).

Results from our study also highlighted that stroke survivors felt lazy or lousy due to their lack of autonomy. The symptoms of the stroke and related dysphagia led to depression and anxiety. Past research, particularly focused on dysphagia, is in corroboration with our study's findings regarding mental health. One study, which focused on dysphagia's impact on the quality of life of participants, revealed that more than half of the study's participants reported that their swallowing difficulties caused their lives to be less enjoyable (Ekberg et al., 2002). Another study involving participants with dysphagia uncovered that clinically relevant symptoms of depression and anxiety were found in 43.7% of all participants (Verdonschot et al., 2013). Research also disclosed that symptoms of depression and anxiety were found in stroke patients during the rehabilitation process; participants of said study had a post-stroke depression prevalence of 31.1% and a post-stroke anxiety prevalence of 20.4% (Schöttke & Giabbiconi, 2015).

### **Limitations**

There are a number of limitations of the current study. Due to COVID-19, recruitment for the study ended prematurely, resulting in a smaller sample of participants. Within the smaller sample, there was a lack of diversity among study participants as all participants were white and non-Hispanic as well as from the same general geographic region. Therefore, results of the study may not be generalizable to populations from different racial or ethnic groups. Culture was also not specifically addressed or assessed in the current study; however, culture may impact an individual's response to and perception of disability and chronic illness. Additionally, due to the

broad nature of the inclusion and exclusion criteria, confounding factors had the potential to impact the results of the study. For example, one caregiver was diagnosed with autism spectrum disorder, which may have affected his perception of caregiver burden and familial support. Lastly, the format of the interviews did not allow for easy comparison between the opinions of the dyad on specific issues to see if there were any additional discrepancies.

### **Implications for Practice**

The findings of the current study suggest the need for personalized medical and psychological support for both members of the dyad. Each dyad encountered different lived experiences with the diagnosis of post-stroke dysphagia—and each member of the dyad went through different lived experiences at times. Therefore, it is imperative that each patient receives individualized medical and psychological support that is realistic for the family, something that was lacking for many of the participants in the current study. For example, consuming thickened liquids proved to be unattainable for several of the participants/families; healthcare professionals should be ready with alternative diet suggestions that allow for easy modification while still retaining the nutritional benefits. Importantly, this requires open and direct communication with the patients and their caregivers, checking in to see whether the medical and therapy recommendations are aligned with their family's goals and needs. Patient autonomy is key when it comes to clinical decision making and recommendations should not be given to the family or stroke survivor without the dyad's input.

The findings of the study also highlight the need for increased resource support in addition to increased transparency from medical professionals considering the clear

impacts of stroke and dysphagia on patient and caregiver mental health. Speech-language pathologists and other medical staff members should provide stroke survivors and caregivers with suggested support groups and referrals to counseling as needed to ensure that there is a smooth transition from the hospital to home environment. Such counseling can also help the survivors and caregivers cope with their feelings of lost autonomy and independence. Ultimately, the mental health of both the stroke survivor and informal caregiver should be taken into consideration as the recovery process affects both members of the dyad. Though past research and healthcare practices have been patient-centered, it is clear that the impact of a stroke can be seen across the family. Results of the current study highlight the importance of holistic care for the entire family.

## **Conclusion**

Post-stroke dysphagia can have a lasting effect on the quality of life of both the stroke survivor and the informal caregiver(s). This qualitative study explored the relationship between post-stroke dysphagia and family dynamics, drawing on individual and dyadic interviews conducted with stroke survivors and their family caregivers. Results revealed a perceived lack of autonomy among the stroke survivors due to their inability to partake in activities they once enjoyed, a lack of appropriate support and individualized guidance from medical professionals, and a toll on the mental health of both the stroke survivors and their family members. In order to maximize the benefits of therapeutic interventions, these findings support the need to integrate psychosocial supports for both survivors and their family caregivers into speech-language pathology interventions.

## **Appendix A: Interview Guide**

The goal of today's interviews is to learn more about the experience of living with dysphagia, or eating and swallowing problems, from the perspective of the individual with dysphagia, the perspective of his or her close family member, and the joint perspective of you both as a family unit. My questions here are only meant to guide this conversation, so please feel free to make any comments or ask any additional questions that you think of as they arise. While the focus of this study is on dysphagia, I encourage you to also reflect on the broader stroke recovery process as well.

### **Dyadic Interview Questions**

(if spousal relationship) How long have you been with your current partner?

(if other family relationship) How long have you two been living together?

Who else would you include in your description of your immediate family?

Has your family mood changed since the stroke? (If yes, probe: How? Examples? If no, probe: Why do think it hasn't?)

How does your family communicate about the stroke and any resulting deficits, including dysphagia? Is your family able to openly discuss the illness? (Probe for examples.)

What are current strengths of your relationship?

In what ways have pre-stroke roles changed for you and your family members since the stroke?

Who is primarily responsible for preparing meals in your household?

Who was primarily responsible for preparing meals in your household prior to the stroke?

How much additional time, on average, does it take to prepare meals?

Is it difficult to modify foods or liquids to the correct consistency at home?

Eating and mealtimes are often very important social activities. How has this experience changed for your family?

What has been the most meaningful aspect(s) of this experience for you individually and for your family? What has been the most difficult aspect(s) of this experience for you individually and for your family?

What advice would you give to another family or families who are dealing with post-stroke dysphagia?

Is there anything that I should have asked you together related to stroke or dysphagia that I did not?

### **Patient Interview Questions**

When did your most recent stroke occur?

Describe the onset of your dysphagia?

What were your feelings/thoughts when you first heard the diagnosis?

What expectations did you have about what dysphagia and the recovery process would be like?

What do you know about the condition and prognosis?

What symptoms are you currently dealing with?

Are there any symptoms of stress that you are dealing with that you think are related to particularly to the dysphagia?

What treatment have you received previously and what treatment are you receiving currently, if any?

Eating and mealtimes are often very important social activities. How has this experience changed for you? (Probe for examples)

How have family members been impacted differently/similarly?

Overall, how have your family relationships been affected by the dysphagia? (Probe for both positive and negative changes)

Do you want people to ask about dysphagia and changes in eating? When they do ask, what is your experience?

Have there been any things that people have said to you with good intentions but have actually felt insensitive to you?

What changes have you had to make since the onset of the dysphagia?

What have you learned about yourself or your family that you did not know before the onset of your dysphagia?

Have you been involved with any support groups? If so, how has that affected you?

In hindsight, what do you wish you knew about early in your process of dealing with dysphagia?



Living with both new and chronic conditions can be very frustrating at times. To whom do you express this? Do you feel like your family members refrain from expressing these kinds of feelings with you?

Are there issues related to your stroke or dysphagia that you think about to yourself, but do not discuss openly? What issues? Why do you keep them to yourself?

What are current strengths of your relationship with your family with whom you live?

In what ways could your relationship be strengthened?

In what ways have pre-stroke roles changed for you and your family members since the stroke?

Is there anything that I should have asked you about related to your stroke or dysphagia that I did not?

### **Caregiver Interview Questions**

Living with both new and chronic conditions can be very frustrating at times. To whom do you express this? Do you feel like your family members refrain from expressing these kinds of feelings with [name of family member who had the stroke]?

Are there issues related to the stroke or dysphagia that you think about to yourself, but do not discuss openly? What issues? Why do you keep them to yourself?

What are current strengths of your relationship with [patient participant's name]?

In what ways could your relationship be strengthened?

In what ways have pre-stroke roles changed for you and your family members since the stroke?

What were your feelings/thoughts when you first heard the diagnosis of dysphagia?

What expectations did you have about what dysphagia and the recovery process would be like?

What changes have you had to make since the onset of the dysphagia?

Have you experienced any increased feelings of burden since [patient participant's name] stroke, particularly as related to dysphagia? For example, burden can be emotional (such as anxiety or sadness), physical (such as pain or fatigue), or financial (such as loss of work productivity or increased costs).

Eating and mealtimes are often very important social activities. How has this experience changed for you?

How have family members been impacted differently/similarly?

Overall, how have your family relationships been affected by the dysphagia? (Probe for both positive and negative changes)

Do you want people to ask about [patient participant's name] dysphagia and changes in eating?

When they do ask, what is your experience?

Have there been any things that people have said to you or your partner with good intentions but have actually felt insensitive to you?

What have you learned about yourself or your family that you did not know before the onset of your dysphagia?

Have you been involved with any support groups? If so, how has that affected you?

In hindsight, what do you wish you knew about early in your process of dealing with dysphagia?

Is there anything that I should have asked you about related to stroke or dysphagia that I did not?

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