

SIG 13**Tutorial**

Integrating Family-Centered Care Into Chronic Dysphagia Management: A Tutorial

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ABSTRACT

Purpose: Chronic illnesses and sources of disability, such as dysphagia, are experienced by the entire family system. A narrow focus on impairment-level treatment cannot account for the often-dramatic shift in biopsychosocial functioning that is experienced by both the individual with dysphagia and their family members. To maximize treatment effectiveness, it is therefore necessary to focus more holistically on family resilience and adaptation. Drawing from the principles of family systems theory and the biopsychosocial-spiritual framework, this tutorial explores the application of family-centered care models to chronic dysphagia management. Using a case study to illustrate dysphagia's impact on family caregivers, we suggest a number of opportunities for speech-language pathologists to appropriately engage in family-centered care.

Conclusions: Clinicians need to recognize that chronic dysphagia's widespread consequences necessitate the integration of the family into intervention plans. This requires a better understanding of family dynamics, particularly as they relate to the medical condition. As part of the management process, clinicians should consider explicitly inquiring about specific sources of support the family may require and make referrals to other professionals as needed. They should also consider implementing strategies to support the family into intervention in a way that minimizes burden and respects their capabilities. It is only through a more family-centered care approach that clinicians will be able to reduce the impacts of third-party disability and improve the lives of patients and their families.

Informal caregivers, frequently family members or close friends, are an integral member of the adult dysphagia management process. Such caregivers often find themselves engaged in a variety of new-to-them tasks, such as managing feeding tubes, preparing specialized diets, taking trainings on the Heimlich maneuver, monitoring daily exercises, and ensuring appropriate oral care. These caregivers also experience similar responsibilities across other therapeutic domains (e.g., physical therapy, language and cognition) and may have simultaneous responsibilities unrelated to care provision (e.g., employment). Unfortunately, the support provided to them as they navigate

these new roles may be limited. Current models of health care, including dysphagia management, generally center on the needs of the "patient" to successfully live at home, failing to recognize the implications of the illness itself and the new care roles on the rest of the family system. To more holistically address the consequences of chronic dysphagia, it is therefore necessary to move beyond the, at times arbitrary, designation of "patient" (who is being treated) and "caregiver" (who is asked to support treatment) and rather consider the family care partnership. Ultimately, clinicians need to determine how to maximally support the resilience of this team.

As written by an interdisciplinary group of two speech-language pathologists (SLPs) and a marriage and family therapist, the purpose of this tutorial is to describe the application of family-centered care models to chronic dysphagia management. After providing an overview of

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the burden of care related to dysphagia, we introduce the biopsychosocial-spiritual model and systems theory as guiding frameworks for the provision of family-centered care. We then offer a case study to illustrate the burden experienced by these caregivers as well as opportunities for the SLP to appropriately engage in family-centered care.

Dysphagia-Related Caregiver Burden

Across the extant literature, a growing body of evidence supports the negative impact dysphagia has on family members. Overall, chronic dysphagia disrupts the daily life of the entire family. As a direct result of the dysphagia, family members, particularly those serving as caregivers, find themselves taking on new roles in the household, spending more time and effort in meal preparation and mealtime assistance, experiencing changes in their family mealtime routines, and decreasing their engagement in social opportunities (e.g., Howells et al., 2021b; Nund et al., 2014a). These caregivers often report that they are unprepared for these new roles and that they wish they had more support, particularly from the health care system across the care trajectory (Nund et al., 2014a). Increased caregiver burden has been associated with the degree of impact the dysphagia is having on mealtime logistics; for example, as the meal duration or degree of diet restrictions increase, there is often a greater impact on the caregiver (Davis et al., 2021). In response to the consequences of dysphagia and these changes in daily life, family members also report increased anxiety and fear (e.g., related to aspiration, choking, weight loss, and nutrition), frustration, stress, embarrassment, and social isolation; changes in relationships; and decreased quality of life overall (e.g., Arslan et al., 2017; Howells et al., 2021b; Lisiecka et al., 2020; Nund et al., 2014a; Perry et al., 2021). Ultimately, these families describe having to adapt to a “new normal” in life since, after all, they are going to “do whatever it takes” to keep their loved one safe, at home, and a member of their family unit (Howells et al., 2021b; Nund et al., 2014a).

Notably, when exploring more general caregiver burden (e.g., “Do you feel increased burden as a result of caregiving?”), dysphagia has been found to be one independent predictor of increased burden, even when controlling for other known burden-related risk factors such as age, gender, and health status (Namasivayam-MacDonald & Shune, 2020; Shune & Namasivayam-MacDonald, 2020b). As a consequence of caregiving, family members often suffer from symptoms of depression and anxiety as well as feelings of frustration, resentment, and anger (e.g., Lwi et al., 2017; Schulz & Sherwood, 2008; Vatter et al., 2018; Watson et al., 2019). In addition, these caregivers experience increased physical multimorbidities (Jacob

et al., 2020) and decreased immunity (Whittaker & Gallagher, 2019). Together, these contribute to decreased physical health, subjective well-being, and quality of life (e.g., LaManna et al., 2020; Or & Kartal, 2019; Pucciarelli et al., 2017). Caregivers may actually be one of the most vulnerable members of the family. Unfortunately, poorer caregiver health and well-being can negatively impact their ability to provide quality care. As a result, the health of the ill family member may further decline, requiring increased informal care needs. Poorer caregiver mental health is actually an independent risk factor for increased patient mortality (Lwi et al., 2017). It is clear that the physical health and quality of life of all members of the care partnership are ultimately interdependent (Lyons & Lee, 2018; Pucciarelli et al., 2017; Shune & Namasivayam-MacDonald, 2020a). Thus, the burden of care associated with managing dysphagia must be considered not only for improving caregiver well-being but also for ensuring the health, well-being, and sustainability of the care partnership as well as the family unit.

Like other chronic conditions, the impact of chronic dysphagia on the larger family system and on caregiver burden can be framed within the World Health Organization’s (WHO’s) conceptualization of “third-party disability” or the realized disability in family members or caregivers that results from their loved one’s chronic illness (WHO, 2001). The WHO’s International Classification of Functioning, Disability and Health (WHO-ICF) framework defines functioning from the perspective of the body, the individual, and the society, allowing us to describe the consequences of a health condition on an individual in the context of their environment. This has contributed to an important expansion in dysphagia service provision as the biomedical effects of dysphagia (e.g., aspiration) are framed within a larger psychosocial context (e.g., impact of modified diets, social isolation and depression), creating treatment plans that consider environment-level factors and target improved quality of life.

Yet, equally as valuable, the WHO-ICF framework can describe the influence of an individual’s health condition, such as dysphagia, on their social context. The anxiety, guilt, and isolation observed in dysphagia caregivers resulting from increased responsibilities, decreased social involvement, and decreased support can be considered as third-party disability (e.g., Arslan et al., 2017; Howells et al., 2021b; Nund et al., 2014a). Importantly, though, not only can dysphagia impact the functioning, activities, and participation of the family, but this third-party disability can, in turn, also influence outcomes of the individual with dysphagia (Shune & Namasivayam-MacDonald, 2020a), similar to what has been observed in other caregiver burden literature (e.g., Lwi et al., 2017; Pucciarelli et al., 2017). Clinicians need to recognize dysphagia as a chronic condition that is experienced by all members of

the care partnership, likely in a cyclical manner, and that the entire family is simultaneously learning to adapt and cope. Ultimately, dysphagia has a significant impact on the everyday lives, relationships, and needs of both the individual with dysphagia and those providing care (e.g., Howells et al., 2021a, 2021b; Nund et al., 2014a, 2014b). This suggests the clear importance of integrating family members into dysphagia management, not just as supporters of the treatment plan but as individuals whose health and well-being must also be prioritized across the care trajectory.

Guiding Frameworks for Family-Centered Care

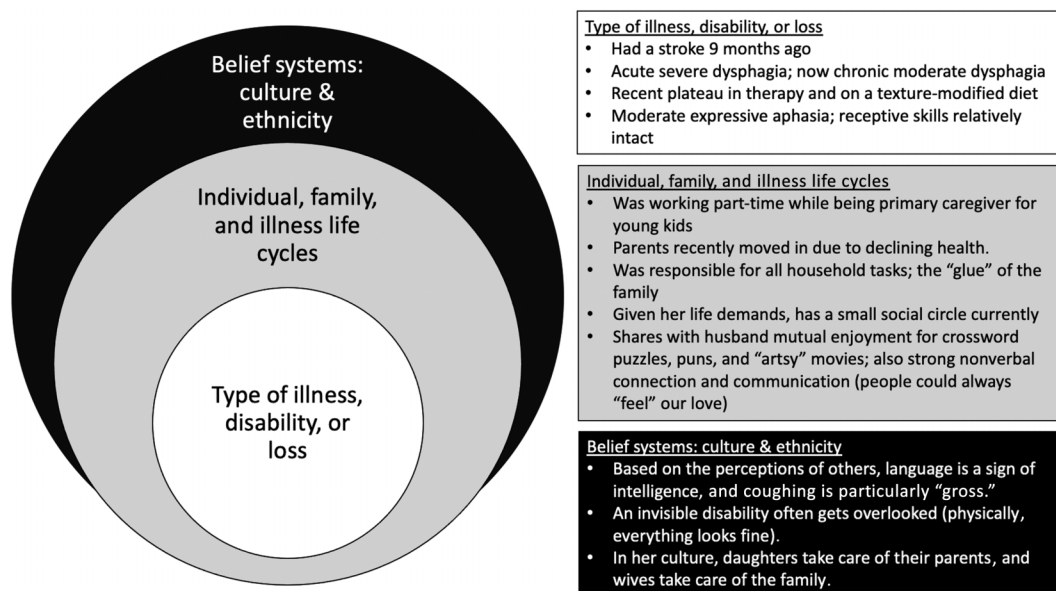
Since dysphagia is rarely experienced solely by the individual, it is helpful to instead conceptualize the entire family caregiving system as experiencing dysphagia and its effects on daily living. After all, the entire family caregiving system must adjust to the “new normal” of altered routines, communication, caretaking patterns, and decision-making processes. Therefore, the entire family ought to be the focus for care and intervention. The biopsychosocial–spiritual model (Rolland, 1994) and systems theory (von Bertalanffy, 1968) provide a framework for which clinicians can conceptualize the adjustments that families need to make within their unique context, so that they can live optimally with dysphagia. Overall, the biopsychosocial–spiritual model considers the psychosocial, physical, and spiritual health of the individual and the caregiving system while recognizing

diverse social locations in a multitude of contexts across the life span (Linville et al., 2017). Systems theory provides a road map for understanding individual functioning within their relational contexts. Clinicians can use systems theory to conceptualize the reciprocal influences between relational functioning and individual health (Weihs et al., 2002).

A biopsychosocial and systems theory framework encourages health care professionals to conceptualize the demands of the illness over time and their intersection with individual and family development and functioning. While the dysphagia itself is a symptom rather than an illness, dysphagia as a chronic condition or source of disability presents with similar challenges as a chronic illness. Thus, it can be beneficial to apply such illness frameworks to the context of chronic dysphagia. Simultaneously targeting the psychosocial and physical demands of an illness along with the strengths and vulnerabilities of the individual and family forms the basis of the Family Systems Illness model (Rolland, 1994), a model that can inform clinical practices in dysphagia management. Figure 1 illustrates how this model can be adapted using biopsychosocial and systems principles within the context of poststroke dysphagia in a hypothetical, middle-aged, Asian female. Such an example highlights the intersection between the chronic condition (impairment, disability), the unique strengths and vulnerabilities of the individual and family, and the larger cultural and environmental influences.

The family caregiving system consists of parts (e.g., couple relationship, sibling subsystem, parent–child relationship) that interact to form a coherent whole; clinicians can

Figure 1. Conceptualizing dysphagia through a biopsychosocial and systems orientation via the Family Systems Illness model, an example (model adapted from Rolland, 1994).



assess system-level processes and patterns that are less or more adaptive (Johnson & Ray, 2016). For example, a family may typically be emotionally distant, place high value on independence, and have more rigid boundaries with outside systems. This family may have a harder time with the acute/crisis phase of an illness due to having not established the relational communication and problem-solving skills necessary to deal with the instrumental and affective demands of the illness. If a clinician can assess or better understand family functioning and knows about these limitations, they can help the family to learn more adaptive communication and problem-solving skills and simultaneously foster greater cohesion. Such a focus on successful adaptation and resilience in light of the chronic condition rather than a sole focus on improving the swallowing impairment may require a paradigm shift for many clinicians.

Clinicians can aim interventions toward maximizing relational health within and between individuals and the caregiving system, thereby increasing communion. Interventions can also be designed to help increase the agency for both the patient and the family caregiving system and to foster adjustment to the chronicity of dysphagia. By applying the biopsychosocial-spiritual model, providers can understand an individual within their community and family context, collaborate thoughtfully with other care providers (both informal and formal), and avoid plaguing patients with the effects of fragmentation in health care systems. For example, the physician, nursing team, rehabilitation therapists, marriage and family therapist, and dietitian can codesign a treatment plan that more holistically considers the patient and family's needs and that evolves through direct communication and engagement with the family. Of importance is the collaboration in treatment planning. That is, the physician's and the nursing team's consideration of the medical needs; the rehabilitation therapists' consideration of the cognitive, physical, speech and language, and swallowing needs; the dietitian's consideration of the nutritional needs; and the marriage and family therapist's consideration of the psychosocial-emotional needs are all occurring in the context of each other, based on shared decision making across the team members and the family. This interdisciplinary framework ultimately provides clinicians and families with a way of thinking that promotes agency and empowerment over a complex and long-term process such as chronic illness/health care conditions. The road map guides a conceptualization and treatment course that aligns with the demands of the illness or source of disability—chronic dysphagia in this case—and how they intersect with the instrumental and affective styles of the family caregiving system (Rolland, 2018). In this way, the family caregiving system can be thought of as the psychosocial-spiritual hub for effectively coping with and adapting to dysphagia-related challenges (Rolland, 2018).

It is important for clinicians to thoroughly assess and correctly conceptualize dysphagia and its effects on biopsychosocial-spiritual functioning and to have a sense of the unique family caregiving system context before deciding on what intervention will be most effective. This will ensure that treatment interventions are in sync with the unique needs and strengths of each family caregiving system. The conceptualization will vary depending on the culture and context in which an individual and the caregiving system reside. The assessment should also emphasize the importance of a biopsychosocial, multilevel treatment team, depending on the severity of symptoms and the level of social support. Clinicians should engage in clinical ethnographic interviewing to better understand family dynamics and discover what is important to the family as a unit while minimizing any preexisting biases (Jenkins & Rojas, 2020; Westby et al., 2003). Going beyond basic case histories, the clinician can encourage and highlight the value of the family's authentic description of their current lived experience with an emphasis on life history narratives, challenging the more traditional impairment/deficit focus and shifting toward a more holistic, contextualized management plan (Pillay & Kathard, 2018). Table 1 offers suggested questions that could be integrated into the assessment process to facilitate this conversation.

Table 1. Sample assessment questions aimed at understanding family functioning in the context of illness (adapted from Rolland, 2018).

Sample prompts
How has the family had to reorganize itself, or how will it need to do so? At present? Over the course of the illness?
When approaching previous challenges or health issues, has the family defined those challenges in “I” or “we” terms?
What relationships have become closer or more distant across the developmental phases of the illness and family?
What are the family's existing strengths? How can that be applied to the current situation?
In what ways have roles had to change for each family member since the diagnosis? Are those roles overtly discussed? Do adjustments need to be made? How does each family member feel about their role in the caregiving system?
What are the beliefs of each family member related to the course and outcome of the illness? What did they each hear and interpret from the conversations? How do family expectations fit with the recommendations of health care providers?
In your cultural or ethnic traditions, how do families typically communicate about illness/disability? Or with health care providers? How does this translate into how health care providers expect families to communicate about illness?
What feelings related to the illness and adaptation are easiest and most difficult for the family to express?
Who does each family member feel comfortable talking to about their feelings and illness-related experiences? Are there aspects of their experience that they feel they should keep secret or should not be shared?
How does the family get things done and who tends to take the lead and over/under function?
What external support does the family have? (As a whole? Individual members?)
How has the illness impacted family activities?

Importantly, just as the dysphagia-related challenges can affect and strain the entire family caregiving system, the family context can also reciprocally influence how the individual is adapting to living with dysphagia. For example, recent work has supported that family environmental factors, such as spouse employment, are significant predictors of dysphagia-related quality of life (Namasivayam-MacDonald et al., in press). Several systems theory concepts that are especially important to consider are that there are covert and overt rules around how a family ought to behave and communicate and feel about health challenges. Clinicians can provide psychoeducation by explaining what implicit and explicit rules are and how all families have them and then ask the family members to identify their family rules that may influence their adaptation to illness. Typically, families can easily name the explicit rules that structure the patterns and behaviors in their family but may need to imagine what a person outside of their family might notice if they were to spend a few days with them. For example, what are the ways by which this “guest” might unintentionally break an implicit rule? These implicit and explicit rules for family functioning are helpful to understand for several reasons. First, it can give the clinician information about how open or closed the caregiving unit is to outside support and guidance, including health care professionals. Second, the implicit rules for communication are often established according to the beliefs, cultural norms, and available resources for each family system. Implicit rules can often be “constraining” and operate to disrupt communication, create emotional distance, and interrupt personal growth and adaptation and, in time, could fracture or even sever relationships (Gillett et al., 2009).

Lastly, it can be beneficial for patients and families to identify and understand roles within the system and how those historical roles have adapted to current conditions as well as been informed by intergenerational beliefs and messages. For example, if the person who has held a primary caregiver role in the family is the one who becomes chronically ill and/or disabled, then the family may have increased difficulty adapting to the chronic illness phase. Identifying and understanding the functionality of these rules and roles can empower the whole family unit to adjust as needed. The clinician is simultaneously provided a road map for intervention strategies that can increase patient and system agency and communion.

Case Study and Application

To further illustrate the application of a more family-centered approach to dysphagia management, the remainder of this tutorial will build off a case study, presented below along with illustrative quotes on living with

chronic dysphagia from the client’s wife that she provided approximately a year following his death. Throughout, we will identify opportunities for the application of concepts from the biopsychosocial–spiritual framework and systems theory, with particular attention paid to implementable actions by the SLP. Importantly, however, full integration of a family-centered approach will also likely require increased interdisciplinary practice to optimally target the biopsychosocial–spiritual needs of the family system. Thus, opportunities for this engagement will also be highlighted.

“Duane” was a 52-year-old timber feller when he experienced his first stroke. At the time of his stroke, he was living in a rural community with his wife of approximately 15 years and his three young children, ranging in age from 7 to 10 years. Duane was very independent and physically active. He owned his own company and enjoyed outdoor activities, such as golf and clam digging. He especially loved spending time with his family and was very engaged in all aspects of his children’s lives. He was also highly involved in his community, helping out anyone in need.

In May, Duane experienced his first stroke: a severe, left frontal–parietal infarct secondary to a carotid artery occlusion. He was discharged to home after this stroke, primarily with persistent speech deficits and mild gait disturbances. That following July, he underwent a right carotid endarterectomy. The day after discharging to home, he experienced a severe basal ganglia hemorrhage, from which it was not initially expected that he would survive. Approximately 4 days after the hemorrhage, Duane developed his first bout of pneumonia, requiring a tracheostomy (trach) a few days later. Prior to Duane’s hospitalizations, he and his wife had discussed not wanting life-sustaining treatment. This was one of the first in a series of challenging decisions for his wife as related to his respiratory and swallowing needs, a decision that she later admitted feeling ill-prepared for. Not long after the trach, Duane received a percutaneous endoscopic gastrostomy feeding tube, replacing his previous nasogastric tube and further highlighting to his family his nonresolving swallowing and respiratory difficulties. After about 3 weeks in the hospital, Duane was moved to an inpatient rehabilitation facility. As his discharge from inpatient rehabilitation approached, staff encouraged his wife to place him in a care facility, in light of the severity of his physical and cognitive needs. However, his wife was adamant to have him return home. She recognized the need to have him continue to be a part of their young family and acknowledged how strongly his own identity was connected to the outdoors. She could not have him feeling like “a caged animal.” As a result, Duane was ultimately discharged home with his trach and feeding tube still in place, first receiving home health therapy and then transitioning to

outpatient. Approximately 1 month after discharge from inpatient rehabilitation, he had his trach and feeding tube removed—2 days after his 53rd birthday, which was his family's target goal. He was placed on a soft-texture diet (e.g., mashed potatoes and gravy, pudding, Jell-O, oatmeal with milk) with thickened liquids. This diet lasted maybe 2 weeks total as:

...within a week, he started transitioning himself to whatever we had in the house... I would monitor as much as possible when he would try new textures... I bought two large cans [of Thick-It] and I didn't even get through one can before finally tossing it.

Duane remained at home, developing "his normalcy" related to eating and dining with his family for the next 20 years of his life.

As Duane's wife reflected on her decades of living with someone with chronic dysphagia, she acknowledged that even though she insisted on acting as his primary caregiver, she still felt it difficult to juggle her many roles (e.g., mother, wife, teacher, cook, chauffeur, caregiver). At times, she felt overwhelmed and frustrated, but she continued her caregiving duties as she felt this was the best thing she could do for her family, not just Duane. When asked if she was afraid of him choking, Duane's wife said that she was "always scared." She recalled that he would often "stand over the sink, drooling," and she would say, "Try and cough." She said he would usually cough up the bolus eventually. While there were several times where he had true asphyxiation that required medical attention, if she had "taken him to the emergency room every time that he had a cough, a choke like that, yeah, it would have been at least once a month." She was also worried that if she took him to the emergency room, she would be judged and ridiculed or shamed for not taking care of him properly, as if she was intentionally trying to harm him by allowing him to eat things that were difficult for him to swallow.

To avoid the choking, she would try to ensure "everything was really cut small," and she incorporated a lot of "softer things." This was difficult because Duane loved hamburgers and other regular solids (per the International Dysphagia Diet Standardisation Initiative [IDDSI]). She recalled one time they had pork chops for dinner: "We ended up in the emergency room, and I thought it really wasn't worth it, but I had thought about it and I did cut them up very small...but just the fast eating that oh my gosh, he would pack his mouth full..."

Duane's wife also shared that she "didn't feel competent" with diet texture modification and "so wished" she had gone to nursing school so she would have the skills needed to care for him. She also wished she could "have a chef in the house that prepared all the food for us

and for him" because she was constantly questioning whether Duane should be eating what she wanted to prepare. While they were given diet texture recommendations that would help avoid airway invasion and improve efficiency, Duane's wife honestly admitted, "I can't say that I tried super hard to follow those things, but it was kind of like I did try and it just didn't seem to fit, so I went with what worked for me and what worked for him." She also reported feeling fearful and uncomfortable trying to balance safety concerns with Duane's food preferences:

It was very difficult for me to restrict him...to take away food from someone and that's all he really wanted. I mean that it's all he really asked for... And I'd let him choose. He wanted to go to Dairy Queen... "Okay, and what do you want?" Well, he'd order the biggest damn hamburger there was [laughter]. And I'd think "holy crapes"...and you know, if I got—if I ordered something different, he was not happy.

When asked about avoiding certain foods, Duane's wife shared that she "always tried to keep things that he would choke on out of sight." Unfortunately, Duane "did get pretty good though at finding things." Duane's wife also felt that their social life changed because of his restrictive diet:

And I don't know if some of that is also because we live on 130 acres. We're not living in town. Possibly if I was living in town, maybe people would have dropped by more... There were two or three that stuck with him, but pretty much a lot of the people I saw, his friends at the funeral or his celebration of life, I had not seen in a number of years, and I understand that. Many of them just wanted to remember him the way he was... We didn't get asked to dinner. I took over the family gatherings, and I have a large family, Christmas, Thanksgiving, those things. Easter. I always cooked because he was so much more comfortable at home.

Duane's wife reported that his dysphagia and incontinence were the biggest barriers to making their life "almost normal even with a brain deficit." She went on to say that "a lot of people don't understand" and that the two conditions "wipe out a lot of social activities." As a result, the family had to "learn to adjust and adapt" as best they could.

When asked about what she did to help relieve some of the burden, Duane's wife said, "Unfortunately, I never took the time to do the services for me. But I had three kids that were going [to therapy]... I really, really tried to keep their life as normal as possible..." However, she felt

like her health care team could have better supported her. Overall, she felt ill-prepared to manage dysphagia and clearly lacked support. She recalled getting the discharge orders:

You know, I think I think, with this dysphagia possibly...you get the discharge orders. You get the list, and I still have a list of what to do, what not to do, you know, and I remember reading them. And that was kind of it. There needs to be some follow-up. There needs to be some checking up. What's working? If somebody just would have said what's working and what's not working for you, it—in any part of his care, whether it be incontinence, whether it be dysphagia, whether it be, you know, uh socializing, you know? What works? What's working? ...and the all-important one is what's not working and how can we help? We don't have that in our care system, unfortunately, or at least I didn't experience that."

Although Duane's wife never explicitly shared that she felt burdened, the increased feelings of distress, fear, and isolation; the loss of social bonds; the negotiation of a new normal; and the lack of support she described are consistent with previous accounts of dysphagia-related caregiver burden (e.g., Arslan et al., 2017; Howells et al., 2021b; Johansson & Johansson, 2009; Lisiecka et al., 2020; Nund et al., 2014a; Patterson et al., 2013; Perry et al., 2021). As such, it is important to critically analyze Duane's wife's experiences and consider how SLPs might have been able to better support her.

When considering family systems theory, it is clear how a stroke survivor with high caregiving needs can destabilize the family system. Duane's unpredictability and need for constant supervision likely distorted much of the family's interactions, and the whole family was forced to adapt to these behaviors. In applying the biopsychosocial-spiritual model to this case, the biological factors are, for example, the brain damage resulting from Duane's strokes as well as the dysphagia and incontinence. Psychological factors that must be considered when developing a treatment plan include, but are not limited to, the pleasure Duane derives from food, the resilience of Duane and his wife as a couple, stressors such as fear of Duane choking and knowledge of appropriate meals, and the demands of having young children at home. It is also critical to consider social and cultural factors such as how their relationships changed with extended family and friends, their loss of a support system since few people visited or invited them out, and the definitions of "appropriate" or "competent" care assigned by the health care system. Lastly, when applicable, the role of spirituality should be considered, which Duane's wife did not mention explicitly in our

conversations. The biopsychosocial-spiritual model allows for an understanding of the needs of Duane and his wife as a care partnership within their community and family contexts and highlights some key factors that should ultimately drive the formulation of a treatment plan.

To help clinicians guide these initial conversations around caregiver functioning and adaptation, they can use a validated tool such as the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES; Shune et al., 2020) across the treatment trajectory as a preliminary screener for dysphagia-related caregiver burden and needs assessment, particularly among informal caregivers of adults experiencing dysphagia. The CARES is a 26-item questionnaire that has two parts that explore aspects of dysphagia's impact on the caregiver over the previous month: a checklist of behavioral and functional changes and a checklist of subjective caregiver stress. Figures 2 and 3 detail the items on each of the checklists, respectively, and note how Duane's wife might have responded given her experiences outlined above.

Importantly, the CARES helps clinicians identify priorities for caregiver intervention, including when referrals are needed. It is not expected that the SLP, or any other clinician using the CARES, is the only one able to address the caregiver's needs. In fact, only a select number of items on the CARES can be targeted by the SLP. Figures 4 and 5 detail what an SLP may be able to target given their scope (indicated by check marks) versus where they would need to make referrals (indicated by an X). Boxes that have both a check mark and an X indicate that an SLP may be able to help target the burden within an intervention in conjunction with another professional, such as a dietitian or another member of the interdisciplinary team.

In looking at Duane's wife's sources of dysphagia-related burden per the CARES (see Figures 2 and 3) as compared with areas that the SLPs can address (see Figures 4 and 5), five primary areas can likely be addressed by the SLP:

1. Part A, Item 1: How to help reduce the time required to prepare meals via training on IDDSI testing procedures.
2. Part A, Item 7: How to participate in meals together by discussing naturally soft or pureed foods that they can both enjoy.
3. Part A, Item 9: How to go out and eat together by helping to identify menus that have several items that Duane can eat and will enjoy and/or items that can be easily modified at the table so that Duane can consume them safely.
4. Part B, Item 1: Better preparation on how to manage Duane's dysphagia via educating his wife on effective cues, prompts, and strategies to minimize

Figure 2. Duane's wife's hypothetical responses for Part A of the Caregiver Analysis of Reported Experiences with Swallowing Disorders: the checklist of behavioral and functional changes. N/A = not applicable.

	IN THE PAST MONTH, HAS THIS SITUATION BOTHERED YOU?		
1. Because of my loved one's swallowing difficulties, extra time is required for mealtimes (e.g., finding appropriate foods, cooking meals, preparing tube feedings, watching my loved one eat/drink).	YES	NO	N/A
2. Because of my loved one's swallowing difficulties, my mealtime- and nutrition-related responsibilities have increased (e.g., related to shopping, cooking, tube feeding).	YES	NO	N/A
3. Because of my loved one's swallowing difficulties, the costs associated with their nutrition-related needs have increased (e.g., supplies for tube feedings, thickening products or thickened liquids, supplements).	YES	NO	N/A
4. Other family members disagree with me about how to best manage my loved one's swallowing difficulties.	YES	NO	N/A
5. Managing my loved one's swallowing difficulties interferes with my daily routine (e.g., job, school work, household chores).	YES	NO	N/A
6. Managing my loved one's swallowing difficulties takes away from other things I would prefer to be doing (e.g., leisure activities).	YES	NO	N/A
7. Because of my loved one's swallowing difficulties, my loved one and I do not participate in meals together as often as we used to.	YES	NO	N/A
8. Because of my loved one's swallowing difficulties, I do not make plans with others as often as I would like.	YES	NO	N/A
9. Because of my loved one's swallowing difficulties, my loved one and I cannot go out to eat as much as I would like.	YES	NO	N/A
10. Because of my loved one's swallowing difficulties, I avoid eating or drinking items that they cannot have.	YES	NO	N/A

choking risks as well as IDDSI testing so that she has more confidence when preparing meals for Duane.

5. Part B, Item 4: Reduce the fear of choking by helping her understand the difference between coughing

and choking as well as teaching her what to do if Duane is choking. This can be supplemented by a cardiopulmonary resuscitation course that will provide Duane's wife with some important skills in case of an emergency.

Figure 3. Duane's wife's hypothetical responses for Part B of the Caregiver Analysis of Reported Experiences with Swallowing Disorders: the checklist of subjective caregiver stress.

	In the past month, has the statement been true for you?	
1. I do not feel prepared to help manage my loved one's swallowing difficulty (e.g., related to tube feeding, thickened liquids, Heimlich).	YES	NO
2. Because of my loved one's swallowing difficulties, I feel like it is hard to ensure they receive adequate nutrition.	YES	NO
3. I feel like my loved one does not do as much as they can to help with their swallowing difficulties.	YES	NO
4. Because of my loved one's swallowing difficulties, I am scared that they will choke.	YES	NO
5. Because of my loved one's swallowing difficulties, I feel guilty eating or drinking items that they cannot have.	YES	NO
6. Because of my loved one's swallowing difficulties, I feel like I don't have enough time to take care of my own physical health.	YES	NO
7. Because of my loved one's swallowing difficulties, I feel like I don't have enough time for activities that make me feel good.	YES	NO
8. Because of my loved one's swallowing difficulties, I feel depressed.	YES	NO
9. Because of my loved one's swallowing difficulties, I feel stressed.	YES	NO
10. Because of my loved one's swallowing difficulties, I feel anxious.	YES	NO
11. I feel embarrassed by my loved one's swallowing difficulties when other people are around.	YES	NO
12. I worry about how my loved one feels about their swallowing difficulties.	YES	NO
13. Because of my loved one's swallowing difficulties, I feel like the social and togetherness aspects of mealtimes are reduced.	YES	NO
14. Because of my loved one's swallowing difficulties, I feel isolated from family and friends.	YES	NO
15. I feel trapped as a result of managing my loved one's swallowing difficulties.	YES	NO
16. I worry that my loved one's swallowing difficulties will not improve.	YES	NO

Figure 4. Items on Part A of the Caregiver Analysis of Reported Experiences with Swallowing Disorders (checklist of behavioral and functional changes) that can be targeted by the speech-language pathologist (SLP).

	TARGET BY SLP?
1. Because of my loved one's swallowing difficulties, extra time is required for mealtimes (e.g., finding appropriate foods, cooking meals, preparing tube feedings, watching my loved one eat/drink).	✓
2. Because of my loved one's swallowing difficulties, my mealtime- and nutrition-related responsibilities have increased (e.g., related to shopping, cooking, tube feeding).	×
3. Because of my loved one's swallowing difficulties, the costs associated with their nutrition-related needs have increased (e.g., supplies for tube feedings, thickening products or thickened liquids, supplements).	×
4. Other family members disagree with me about how to best manage my loved one's swallowing difficulties.	✓
5. Managing my loved one's swallowing difficulties interferes with my daily routine (e.g., job, schoolwork, household chores).	×
6. Managing my loved one's swallowing difficulties takes away from other things I would prefer to be doing (e.g., leisure activities).	×
7. Because of my loved one's swallowing difficulties, my loved one and I do not participate in meals together as often as we used to.	✓
8. Because of my loved one's swallowing difficulties, I do not make plans with others as often as I would like.	×
9. Because of my loved one's swallowing difficulties, my loved one and I cannot go out to eat as much as I would like.	✓
10. Because of my loved one's swallowing difficulties, I avoid eating or drinking items that they cannot have.	×

Figure 5. Items on Part B of the Caregiver Analysis of Reported Experiences with Swallowing Disorders (checklist of subjective caregiver stress) that can be targeted by the speech-language pathologist (SLP).

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

As may be evident from the list above, there are some very simple ways clinicians can help to relieve some feelings of burden once they understand what is causing the burden. This underscores the importance of asking caregivers questions about how they are doing and tailoring the communication to them to help with information processing and caregiver engagement (Longacre et al., 2015). When providing education, SLPs need to be careful to not provide education that is highly medicalized and generic (Nund et al., 2014a). Instead, clinicians should use layman's terms and explain new information in detail. To not overwhelm the caregiver or the patient, clinicians should also consider writing down or providing handouts that reiterate whatever is being conveyed verbally and be mindful of the number of tasks or activities being assigned at the same time. The National Foundation of Swallowing Disorders (www.swallowingdisorderfoundation.com) and IDDSI (www.iddsi.org) websites both have several web pages, handouts, and videos that may be useful for this purpose. Duane's wife might have found the IDDSI handouts and videos useful when preparing meals for Duane. The free webinars and support groups offered through the National Foundation of Swallowing Disorders may have further helped support Duane's wife's feelings of inadequacy, isolation, and lack of support.

Depending on the state of the caregiver and how stable the care recipient's condition is, it may also be beneficial to help caregivers develop what are called "problem-focused strategies," that is, guiding them to confront issues and seek information themselves to improve self-efficacy, moving them away from emotion-focused coping strategies that often involve worry and self-accusation (Forde & Pearlman, 1999). Motivational interviewing can be one particularly useful technique to facilitate these conversations and increase self-efficacy. This process may have better empowered Duane's wife when she felt like she needed the skills of a registered nurse and may have played a role in the family's consideration of the potential benefits and consequences of dietary modification. To further promote agency and self-efficacy, clinicians should also consider health literacy and evaluate the family's learning and understanding. Use of formal strategies, such as the teach-back method, can promote efficient and effective communication and information delivery between the health care professional and the family, empowering family members to gain competence in the skills being trained (Talevski et al., 2020).

It is also important to note that although there are factors contributing to burden that cannot be directly addressed by the SLP, they may be interacting with what is happening within the therapy sessions. For example, if someone is experiencing increased stress, anxiety, depression, and guilt, it may be more difficult for them to recall what is spoken about during sessions, engage in therapy,

and even develop questions to ask regarding the therapists' recommendations. Thus, beyond tailoring communication to meet these family members where they are at during that particular moment in time as described above, it is crucial to also ensure their psychosocial needs are being acknowledged and met. Assisting them to set up counseling sessions, which could take place at the same time as the speech therapy session, could facilitate attendance, engagement, and a prioritization of their own health. Working directly with marriage and family therapists or other appropriate counselors, including co-treatment, can target family functioning while clearly signaling to the family that their overall well-being is valued. For example, in the case of Duane's wife, it appeared as though the swallowing difficulties were negatively impacting her own health, ability to make plans with others, and engagement in activities she enjoys while increasing her guilt, stress, and isolation (see Figures 2 and 3). A therapist or counselor would be able to target her emotional responses to these consequences of dysphagia and potentially explore how they also impact the family's dynamics overall. These counseling sessions could have provided Duane's wife the space to disclose how she was coping with the changes happening in her household, as related to both the chronic dysphagia and the larger stroke recovery process. A dietitian could have also been a valuable member of the interdisciplinary team, supporting conversations around Duane's nutrition, particularly as related to Duane's current eating patterns and the mealtime patterns of the family overall. Finally, it is important to highlight the judgment Duane's wife indicated feeling from health care providers in general, that is, as if she was not taking care of him "properly." Such a vulnerable admission clearly necessitates improved education of the larger health care team (e.g., physicians, nursing team) surrounding the importance of autonomy in meals and quality of life.

Given that Duane's wife valued quality of life, their family found ways to accommodate the chronic dysphagia that worked for them, even though this may have gone against the recommendations of the SLP and the team. It is important for health care professionals to consider that recommendations are just that—recommendations—and that, ultimately, the patient and their family have the final say on what they comply with based on what works for them and their overall family functioning. It is the clinician's job to explain both the benefits of the recommendations and the adverse outcomes associated with noncompliance (Low et al., 2001), so that the patient and their family can make an informed decision. However, if lack of compliance is not a choice made by the family and is an issue related to health care team functioning, as suggested in one study looking at compliance in stroke survivors with dysphagia (Smith-Tamaray et al., 2011), then

there are a few ways this can be addressed. A recent conceptual model describing adherence to dysphagia treatment suggests that modifiable factors that could ultimately improve adherence include access to treatment, type of treatment, patient perceptions of the benefits of treatment, self-efficacy, motivation, health literacy, support factors, and provider bias (Krekeler et al., 2020). Thus, it is the health care team's responsibility to engage in conversation with these families to explore the factors and develop a plan that best meets the family's needs.

Overall, SLPs and the other members of the interdisciplinary team must be explicit with the families they are working with such that they recognize both the physical and psychoemotional consequences of dealing with chronic dysphagia and begin to normalize these experiences. Ultimately, exploring opportunities to enhance family resilience will maximize therapeutic outcomes, including those directly related to dysphagia management.

Conclusions

This tutorial provided an overview of the importance of family-centered care as it relates to dysphagia management from the authors' perspectives as two SLPs and a marriage and family therapist. It is critical that clinicians recognize that dysphagia's consequences are widespread and will ultimately impact the whole family. As such, they must consider how they can integrate the family into the intervention plan. First, clinicians must better understand the family dynamics as they relate to the patient condition through family systems theory and a biopsychosocial-spiritual framework. Next, they must inquire about the specific sources of support the family may require. This can be done either informally by asking the family directly or through a tool such as the CARES (Shune et al., 2020). The clinicians must then determine if referrals to other professionals are needed to address sources of burden or support that are outside the SLP's scope and/or abilities. Finally, they must consider how they can integrate strategies to support the family into the intervention in a way that minimizes burden, respects their capabilities, and ultimately improves quality of life for both the patient and their caregivers. It is only through this family-centered care approach that clinicians will be able to reduce the impacts of third-party disability and improve the lives of both their patients and their patients' families.

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References

- Arslan, S. S., Demir, N., & Karaduman, A. A. (2017). The anxiety level of caregivers of neurological patients with dysphagia. *Dysphagia*, 32(4), 570–574. <https://doi.org/10.1007/s00455-017-9801-7>
- Davis, C., Namasivayam-MacDonald, A. M., & Shune, S. E. (2021). Contributors to poststroke dysphagia-related caregiver burden. *American Journal of Speech-Language Pathology*, 30(3), 1061–1073. https://doi.org/10.1044/2021_AJSLP-20-00250
- Forde, O. T., & Pearlman, S. (1999). Breakaway: A social supplement to caregivers' support groups. *American Journal of Alzheimer's Disease & Other Dementias*, 14(2), 120–124. <https://doi.org/10.1177/153331759901400206>
- Gillett, K. S., Harper, J. M., Larson, J. H., Berrett, M. E., & Hardman, R. K. (2009). Implicit family process rules in eating-disordered and non-eating-disordered families. *Journal of Marital and Family Therapy*, 35(2), 159–174. <https://doi.org/10.1111/j.1752-0606.2009.00113.x>
- Howells, S. R., Cornwell, P. L., Ward, E. C., & Kuipers, P. (2021a). Client perspectives on living with dysphagia in the community. *International Journal of Speech-Language Pathology*, 23(2), 201–212. <https://doi.org/10.1080/17549507.2020.1765020>
- Howells, S. R., Cornwell, P. L., Ward, E. C., & Kuipers, P. (2021b). Living with dysphagia in the community: Caregivers "do whatever it takes." *Dysphagia*, 36(1), 108–119. <https://doi.org/10.1007/s00455-020-10117-y>
- Jacob, L., Oh, H., Shin, J. I., Haro, J. M., Vancampfort, D., Stubbs, B., Jackson, S. E., Smith, L., & Koyanagi, A. (2020). Informal caregiving, chronic physical conditions, and physical multimorbidity in 48 low- and middle-income countries. *The Journals of Gerontology: Series A*, 75(8), 1572–1578. <https://doi.org/10.1093/geronol/glaa017>
- Jenkins, K., & Rojas, R. (2020). Developing cultural competence from a Funds of Knowledge framework: Ethnographic interviewing revisited. *Perspectives of the ASHA Special Interest Groups*, 5(6), 1683–1686. https://doi.org/10.1044/2020_persp-20-00081
- Johansson, A. E. M., & Johansson, U. (2009). Relatives' experiences of family members' eating difficulties. *Scandinavian Journal of Occupational Therapy*, 16(1), 25–32. <https://doi.org/10.1080/11038120802257195>
- Johnson, B. E., & Ray, W. A. (2016). Family systems theory. In C. L. Shehan (Ed.), *The Wiley Blackwell encyclopedia of family studies*. Wiley. <https://doi.org/10.1002/9781119085621.wbef130>
- Krekeler, B. N., Vitale, K., Yee, J., Powell, R., & Rogus-Pulia, N. (2020). Adherence to dysphagia treatment recommendations: A conceptual model. *Journal of Speech, Language, and Hearing Research*, 63(6), 1641–1657. https://doi.org/10.1044/2020_JSLHR-19-00270
- LaManna, J. B., Unruh, L., Chisholm, L., Pericles, P., & Fotovvat, H. (2020). Perceptions of health and well-being among older adult caregivers: Comparisons of current caregivers with former and never caregivers. *Geriatric Nursing*, 41(4), 429–435. <https://doi.org/10.1016/j.gerinurse.2020.01.015>
- Linville, D., Hodgson, J., & Lamson, A. (2017). Medical family therapy. In J. Lebow, A. Chambers, & D. C. Breunlin (Eds.), *Encyclopedia of couple and family therapy* (pp. 1–11). Springer. https://doi.org/10.1007/978-3-319-15877-8_578-1

- Lisiecka, D., Kelly, H., & Jackson, J. (2020). 'This is your golden time. You enjoy it and you've plenty time for crying after': How dysphagia impacts family caregivers of people with amyotrophic lateral sclerosis—A qualitative study. *Palliative Medicine*, 34(8), 1097–1107. <https://doi.org/10.1177/0269216320932754>
- Longacre, M. L., Galloway, T. J., Parvanta, C. F., & Fang, C. Y. (2015). Medical communication-related informational need and resource preferences among family caregivers for head and neck cancer patients. *Journal of Cancer Education*, 30(4), 786–791. <https://doi.org/10.1007/s13187-015-0814-3>
- Low, J., Wyles, C., Wilkinson, T., & Sainsbury, R. (2001). The effect of compliance on clinical outcomes for patients with dysphagia on videofluoroscopy. *Dysphagia*, 16(2), 123–127. <https://doi.org/10.1007/s004550011002>
- Lwi, S. J., Ford, B. Q., Casey, J. J., Miller, B. L., & Levenson, R. W. (2017). Poor caregiver mental health predicts mortality of patients with neurodegenerative disease. *Proceedings of the National Academy of Sciences of the United States of America*, 114(28), 7319–7324. <https://doi.org/10.1073/pnas.1701597114>
- Lyons, K. S., & Lee, C. S. (2018). The theory of dyadic illness management. *Journal of Family Nursing*, 24(1), 8–28. <https://doi.org/10.1177/1074840717745669>
- Namasivayam-MacDonald, A. M., Ayub, A., Najeel, H., & Shune, S. (in press). Understanding the independent predictors of dysphagia-related quality of life in stroke survivors. *Journal of Speech, Language, and Hearing Research*.
- Namasivayam-MacDonald, A. M., & Shune, S. E. (2020). The influence of swallowing impairments as an independent risk factor for burden among caregivers of aging parents: A cross-sectional study. *Geriatric Nursing*, 41(2), 81–88. <https://doi.org/10.1016/j.gerinurse.2019.06.008>
- Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014a). Carers' experiences of dysphagia in people treated for head and neck cancer: A qualitative study. *Dysphagia*, 29(4), 450–458. <https://doi.org/10.1007/s00455-014-9527-8>
- Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014b). The lived experience of dysphagia following non-surgical treatment for head and neck cancer. *International Journal of Speech-Language Pathology*, 16(3), 282–289. <https://doi.org/10.3109/17549507.2013.861869>
- Or, R., & Kartal, A. (2019). Influence of caregiver burden on well-being of family member caregivers of older adults. *Psychogeriatrics*, 19(5), 482–490. <https://doi.org/10.1111/psyg.12421>
- Patterson, J. M., Rapley, T., Carding, P. N., Wilson, J. A., & McColl, E. (2013). Head and neck cancer and dysphagia; caring for carers. *Psycho-Oncology*, 22(8), 1815–1820. <https://doi.org/10.1002/pon.3226>
- Perry, S. E., Borders, J. C., Dakin, A. E., & Troche, M. S. (2021). Characterizing quality of life in caregivers of people with Parkinson's disease and dysphagia. *Dysphagia*. Advance online publication. <https://doi.org/10.1007/s00455-021-10299-z>
- Pillay, M., & Kathard, H. (2018). Renewing our cultural borderslands. *Topics in Language Disorders*, 38(2), 143–160. <https://doi.org/10.1097/tld.0000000000000151>
- Pucciarelli, G., Vellone, E., Savini, S., Simeone, S., Ausili, D., Alvaro, R., Lee, C. S., & Lyons, K. S. (2017). Roles of changing physical function and caregiver burden on quality of life in stroke: A longitudinal dyadic analysis. *Stroke*, 48(3), 733–739. <https://doi.org/10.1161/STROKEAHA.116.014989>
- Rolland, J. S. (1994). *Families, illness, & disability: An integrative treatment model*. Basic Books.
- Rolland, J. S. (2018). *Helping couples and families navigate illness and disability: An integrated approach*. Guilford Press.
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, 44(Suppl. 3), 105–113. <https://doi.org/10.5175/JSWE.2008.773247702>
- Shune, S. E., & Namasivayam-MacDonald, A. M. (2020a). Dysphagia-related caregiver burden: Moving beyond the physiological impairment. *Perspectives of the ASHA Special Interest Groups*, 5(5), 1282–1289. https://doi.org/10.1044/2020_PERSP-20-00067
- Shune, S. E., & Namasivayam-MacDonald, A. M. (2020b). Swallowing impairments increase emotional burden in spousal caregivers of older adults. *Journal of Applied Gerontology*, 39(2), 172–180. <https://doi.org/10.1177/0733464818821787>
- Shune, S. E., Resnick, B., Zarit, S. H., & Namasivayam-MacDonald, A. M. (2020). Creation and initial validation of the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) screening tool. *American Journal of Speech-Language Pathology*, 29(4), 2131–2144. https://doi.org/10.1044/2020_AJSLP-20-00148
- Smith-Tamaray, M., Wilson, L., & McAllister, L. (2011). Factors affecting dysphagia management and compliance with recommendations in non-metropolitan healthcare settings. *International Journal of Speech-Language Pathology*, 13(3), 268–279. <https://doi.org/10.3109/17549507.2011.573575>
- Talevski, J., Wong Shee, A., Rasmussen, B., Kemp, G., & Beauchamp, A. (2020). Teach-back: A systematic review of implementation and impacts. *PLOS ONE*, 15(4), e0231350. <https://doi.org/10.1371/journal.pone.0231350>
- Vatter, S., McDonald, K. R., Stanmore, E., Clare, L., McCormick, S. A., & Leroi, I. (2018). A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. *Age and Ageing*, 47(4), 604–610. <https://doi.org/10.1093/ageing/afy049>
- von Bertalanffy, L. (1968). *General system theory: Foundations, development, applications*. George Braziller.
- Watson, B., Tatangelo, G., & McCabe, M. (2019). Depression and anxiety among partner and offspring carers of people with dementia: A systematic review. *The Gerontologist*, 59(5), e597–e610. <https://doi.org/10.1093/geront/gny049>
- Weihls, K., Fisher, L., & Baird, M. (2002). Families, health, and behavior: A section of the commissioned report by the Committee on Health and Behavior: Research, Practice, and Policy Division of Neuroscience and Behavioral Health and Division of Health Promotion and Disease Prevention Institute of Medicine, National Academy of Sciences. *Families, Systems, & Health*, 20(1), 7–46. <https://doi.org/10.1037/h0089481>
- Westby, C., Burda, A., & Mehta, Z. (2003). Asking the right questions in the right ways. *The ASHA Leader*, 8(8), 4–17. <https://doi.org/10.1044/leader.FTR3.08082003.4>
- Whittaker, A. C., & Gallagher, S. (2019). Caregiving alters immunity and stress hormones: A review of recent research. *Current Opinion in Behavioral Sciences*, 28, 93–97. <https://doi.org/10.1016/j.cobeha.2019.02.002>
- World Health Organization. (2001). *The International Classification of Functioning, Disability and Health: ICF*.