Dysphagia-Related Caregiver Burden: Moving Beyond the Physiological Impairment

Samantha Shune, PhD, CCC-SLP\textsuperscript{a} and Ashwini Namasivayam-MacDonald, PhD, CCC-SLP\textsuperscript{b}

\textsuperscript{a} Communication Disorders and Sciences, University of Oregon, Eugene, OR, United States
\textsuperscript{b} School of Rehabilitation Sciences, McMaster University, Hamilton, ON, Canada

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

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

Funding: Portions of this work were supported by an Advancing Academic-Research Careers Award from the American Speech-Language-Hearing Association (PI: S. Shune).
Abstract

Purpose: The biopsychosocial ramifications of dysphagia are widespread. However, its influence on informal caregivers and families is often overlooked. Ultimately, the health and well-being of an entire family is central to care provision. This tutorial introduces readers to the current literature on dysphagia-related caregiver burden and third-party disability, illustrates the consequences of such burden on both caregivers and patients, and suggests strategies for better supporting patients’ informal caregivers.

Conclusion: It is essential that speech-language pathologists recognize that the consequences of dysphagia are not limited to the impairment itself and acknowledge dysphagia’s substantial impact on the entire family system. More general healthcare literature suggests that asking caregivers individual questions, modifying the language used to talk with them, providing them with targeted education and resources, and organizing support groups may all be beneficial for increased perceived support and self-efficacy. Ultimately, in order to best meet the needs of our patients with dysphagia we must also better meet the needs of their families and other informal caregivers.
Introduction

Dysphagia is a debilitating condition that is commonly associated with several illnesses and diseases, including, but not limited to, stroke (Takizawa et al., 2016), dementia (Affoo et al., 2013), head and neck cancer (Hutcheson et al., 2019), ALS (Tabor & Plowman, 2019), and brain injury (Takizawa et al.). Although not considered an illness nor a disease, changes to the swallowing mechanism are also associated with aging. Research has suggested that we can expect changes to the oral cavity, pharynx and larynx as we age, such as: reduced oral sensation (Calhoun et al., 1992), increased duration of oropharyngeal swallowing (Robbins et al., 1992), increased pharyngeal lumen size (Molfenter et al., 2015), increased duration of swallow apnea (Leslie et al., 2005), and reduced maximum isometric tongue pressures (Fei et al., 2013). Generally, these changes have no functional implications for older adults, but the implications can be compounded in the presence of an illness or disease. Therefore, in addition to managing the disease itself, many older adults are also trying to navigate how to swallow safely and efficiently in the presence of pathophysiological changes brought on by their medical condition. Given the many challenges associated with aging, dysphagia, and chronic illness or disease, including maintaining adequate nutrition and hydration, many older adults require external supports.

Overall, there is a growing reliance on informal caregivers in order to meet the needs of older adults with dysphagia and other chronic health conditions (Broese van Groenou & De Boer, 2016; He et al., 2016). These unpaid, family caregivers allow older adults to continue to reside at home safely despite the presence of medical conditions that prevent them from being able to independently care for themselves. In addition to the vast realized benefits among
these older adult care recipients, including decreased mortality and improved psychosocial well-being (Elkan et al., 2001; Gardner, 2011; Sabia, 2008; Wiles et al., 2012), such informal caregiving saves the American healthcare system approximately $470 billion annually (Reinhard et al., 2019). Unfortunately, the burden of care placed on these caregivers is often high and limited clinical attention is paid to this “invisible workforce”, as the healthcare system frequently assumes that these individuals are inherently capable of performing the caregiver role. As a consequence of providing care, informal caregivers, such as spouses and children, experience higher levels of emotional, financial, and physical difficulties, which ultimately impact their overall health. These caregivers often suffer from symptoms of depression and anxiety, experience physical multimorbidities and decreased physical health, demonstrate increased biomarkers of chronic stress and decreased immunity, and report lower levels of self-efficacy and subjective well-being (Allen et al., 2017; Jacob et al., 2020; Kiecolt-Glaser et al., 1991; LaManna et al., 2020; Pinquart & Sorensen, 2003; Schulz et al., 1997). Caregivers are also less likely to monitor their own healthcare and individual needs (Schulz et al., 1997; Schulz et al., 1995). With worsening caregiver well-being, caregivers may become less able to provide quality care, negatively impacting care recipient health and resulting in even greater caregiving needs (Torti et al., 2004; Wolff et al., 2016). Thus, the cycle continues (Figure 1), suggesting this model of care is not sustainable as currently practiced. Ultimately, the physical health and quality of life of both the caregiver and care recipient are interdependent (Lyons & Lee, 2018; Pucciarelli et al., 2017). At issue is how to best support the needs of our patients and their caregivers in order to maximize health and quality of life. Identifying sources of caregiver
burden in order to guide more targeted intervention development is thus a clear health priority.

Third-Party Disability Among Caregivers

The consideration of caregiver burden in our clinical practice requires a paradigm shift from a focus on impairment-level consequences of a disease within a single individual toward a more comprehensive model of that disease in context. Ultimately, chronic illness and disability are universal human experiences that fundamentally alter the everyday lives and psychosocial well-being of an entire family, particularly as a family member assumes the role of informal caregiver. Such illness and disability alter routines, communication, belief systems, caregiving patterns, and family decision-making (Rolland, 2012). Given the presence of challenges associated with functional daily tasks and emotional well-being, in addition to required
adjustments and uncertainties associated with the condition that extend into the distant future, a serious psychosocial strain on the family unit is often unavoidable (Rolland, 1994, 2012, 2017). Within a biopsychosocial-spiritual model (Rolland, 1994, 2017), it is apparent that maximizing health outcomes within and between individuals and their families ultimately requires bridging the psychological, physical, social, and spiritual health of the entire family (Linville et al., 2017). As such, a given illness or disability must be framed within context, incorporating the needs of both the individual and family based on their dynamics, where they are in their life cycle, and the broader belief systems and cultures surrounding the family. Family members’ needs should be prioritized as a necessary aspect to interventions, not just because family is providing care and serving as the central support network for the patient. As clinicians we need to bear in mind that family members are individuals who are also experiencing the chronic illness and present with their own healthcare needs.

This negative impact on the overall family system likely contributes to what has been termed “third-party disability,” or the disability of family members due to the health condition of their significant other (World Health Organization, 2011). In other words, even those otherwise healthy family members may experience activity limitations and participation restrictions as a result of their significant other’s impairment and/or disability. Such third-party disability has been conceptualized within the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) framework across a number of populations relevant to speech-language pathologists, including family members of people with dysphagia (Nund et al., 2016), close family members of people with aphasia (Grawburg et al.,
2013), and spouses of older people with hearing impairment (Scarinci et al., 2003), supporting the clear presence of this phenomenon.

Specific to dysphagia, family members of individuals experiencing head and neck cancer and other neurologic conditions (e.g., stroke) often experience changes in daily routines and mealtime activities, increased feelings of distress, fear, frustration, sadness, and isolation, a loss of social bonds, and decreased life satisfaction and quality of life (Arslan et al., 2017; Johansson & Johansson, 2009; Nund et al., 2016; Nund, Ward, et al., 2014; Patterson et al., 2013; Penner et al., 2012). Providing care for an individual with dysphagia may indeed come with high demands – including the need to prepare different meals and/or tube feedings, assist with daily exercises, monitor nutrition, hydration, and safety strategies, document daily activities, and provide significant social and emotional support. Further, mealtimes and food-related practices are inherently biopsychosocial, serving the important role of supplying necessary nutrition while simultaneously serving as a primary site for interpersonal involvement and social connections. It is not surprising, therefore, that the disruptions to daily life stemming from dysphagia contribute to psychosocial disability across an entire family and, in particular, caregivers. Notably, a recent systematic review of the, albeit limited, literature specifically identified varying degrees of increased burden among carers of older adults with dysphagia, although objective conclusions regarding prevalence or specific causes of burden could not be discerned (Namasivayam-MacDonald & Shune, 2018). Together, these bodies of work support the conceptualization of dysphagia as a chronic health condition that occurs within a larger social context, resulting in a network of individuals (e.g., care recipients and family caregivers) simultaneously experiencing interrelated disability (Figure 2). Additionally, this literature
preliminarily suggests dysphagia as one contributor to the broader caregiver burden experience.

Dysphagia-Related Caregiver Burden

Similar to the broader burden literature, though, there has been far less clinical and research focus on caregivers of individuals with dysphagia themselves. A literature review by Sullivan (2008) cited that the majority of published literature discussing dysphagia in older adults focuses primarily on care recipients, with limited attention given to the needs of the family. Sullivan states that family caregivers should be a focus during planning and treatment of dysphagia, in order to optimize outcomes. Unfortunately, no tools currently exist to screen for or evaluate caregiver burden related to swallowing difficulties, making it difficult to incorporate such measures into research and clinical practice. There is a tool, however, that evaluates compliance with dysphagia-related speech-language pathologist (SLP) recommendations of
caregivers of individuals admitted to rehabilitation and long-term care nursing facilities (Colodny, 2008). While identifying caregiver difficulties in complying with SLP recommendations may in turn help to identify sources of burden, we do not know if this will allow for the identification of dysphagia-related burden in and of itself. Further, this tool was validated on a narrow range of caregivers, specifically those caregivers of individuals not living with their care recipients.

Despite the lack of a standardized method to identify dysphagia-related caregiver burden, researchers have increasingly begun to consider the relationship between caregiver burden and dysphagia and other eating-related difficulties. One study by Riviere and colleagues (2002) evaluated how caregiver burden contributes to aversive feeding behaviors in care recipients with Alzheimer’s disease. They found that caregiver burden was an independent predictor of aversive feeding behaviors, suggesting that caregiver stress unintentionally negatively impacts the care recipient. This highlights the interdependent nature of caregiver and care recipient health. Another study looking at caregivers of stroke patients found that these caregivers tend to suffer from severe burden due to feeling ill-equipped to manage dysphagia and prevent aspiration pneumonia (Byeon, 2019). Yet another study evaluated anxiety levels in caregivers of patients with neurological impairments with and without dysphagia (Arslan et al., 2017). Not surprisingly, they found that caregivers of patients with dysphagia had higher anxiety than those without dysphagia.

More recent research has attempted to determine type and extent of burden experienced by family caregivers of older adults with dysphagia (Namasivayam-MacDonald & Shune, 2019; Shune & Namasivayam-MacDonald, 2020). One article looked at caregivers of
aging spouses and the other looked at caregivers of aging parents. These articles both extracted data from the National Health and Aging Trends Study and the National Study of Caregiving. These national, longitudinal studies interview Medicare recipients across the United States. As part of these studies, caregivers were asked to indicate the presence of emotional, financial and physical burden and rate the severity of each type of burden. As a proxy measure for dysphagia status, care recipients were asked if they had any swallowing difficulties over the past month. Additional demographic information was also collected from caregivers and care recipients including age, gender, underlying medical conditions, current health status, and caregiving provided/received. When all these factors and other known burden risk factors were accounted for, both studies found dysphagia to be an independent predictor of burden in caregivers. Interestingly, caregivers of aging spouses with dysphagia reported experiencing more emotional burden (Shune & Namasivayam-MacDonald, 2020) and caregivers of aging parents reported experiencing increased physical burden in addition to emotional burden (Namasivayam-MacDonald & Shune, 2019). Unfortunately, the data analyzed did not allow for the determination of the exact sources of burden. One might hypothesize that while both groups felt emotionally burdened by the dysphagia, children of aging parents might feel an additional physical burden due to the fact that they may be balancing multiple roles, including caring for their own families and/or employment. This is consistent with the cognitive role theory (Biddle, 1986), which suggests that there are social expectations and social scripts of family roles that dictate how we view ourselves and others within certain roles. For example, some cultures and societies may expect children to care for their aging parents, regardless of their other responsibilities.
Work performed by Patterson and colleagues and Nund and colleagues analyzing the impact of dysphagia on caregivers of head and neck cancer patients also provides some insights in terms of potential sources of emotional and physical burden (Nund, Ward, et al., 2014; Patterson et al., 2013). Patterson and colleagues (2013) analyzed data from 96 caregivers who completed the Caregiver Quality of Life Index- Cancer (CQOLC), which assesses the caregiver’s quality of life, in terms of physical, social, emotional and financial aspects of well-being, and functioning. This study found that caregivers found it stressful to monitor their care recipient’s health status, including changes to eating and drinking. They felt a responsibility for the amount of food the care recipient consumed, particularly in the presence of weight loss. These sources of stress could be considered sources of emotional burden. They also discussed the amount of thought and preparation that meals now required, including the need to make several different versions of a meal to accommodate the whole family. Caregivers cited concerns over producing different food consistencies, providing a varied diet, ensuring the food had sufficient nutrients, and making modified foods palatable and look appealing. Patterson also found that caregivers felt a lack of “togetherness” at mealtimes in the presence of dysphagia, and guilt amongst caregivers in being able to eat and enjoy food. Many caregivers also mentioned attending fewer social events because many of them centered around food and eating. Nund and colleagues (2014) have similarly found that dysphagia profoundly disrupts the life of the caregiver in regards to meal preparation, family life, socializing, and eating out, and evokes numerous emotional responses. This study also found that caregivers felt unprepared to deal with the consequences of dysphagia. Caregivers felt like they needed to adjust and adapt to their partner’s dysphagia with few, if any, formal supports. Nund and colleagues (2016) further
mapped their findings onto the ICF framework, revealing that most commonly reported issues fell within the Activities and Participation domain, including interpersonal interactions and relationships, domestic life, community, self-care, and social and civic life – similar to the reported impact of dysphagia on the patients themselves (Figure 2). While all of these studies were focused on caregivers of head and neck cancer patients, there are some general themes that could be true of any caregiver of a patient with dysphagia. It appears that a lack of knowledge surrounding dysphagia, a lack of education on how to best support the care recipient to eat and drink safely, and general feelings of frustration and guilt may all contribute to the third-party disability experienced by caregivers of individuals with dysphagia and ultimately increase burden.

**Supporting Caregivers**

As clinicians, it is critical that we understand areas of need in order to best support caregivers to, in turn, support our patients. We rely on caregivers to take on responsibilities such as implementing swallowing strategies and diets and monitoring safety and nutritional intake. Yet, it is also clear from the larger burden literature that the health of caregivers and care recipients is ultimately interdependent. Caregiver support is an area that remains underexplored in the dysphagia research. Thus, it is necessary to pull from other fields focusing on, for example, caregivers of patients with cancer and dementia, in order to learn best practices for providing caregivers with the skills, education and resources required to reduce burden and optimize patient care. A systematic review evaluating supports provided to caregivers of head and neck cancer patients identified a few common themes for caregiver interventions (Harding & Higginson, 2003). These included: home care, respite care provision,
promotion of social networks and activities, one-on-one interventions for caregivers, and support groups for caregivers. While we may need to make referrals to a social worker in order to determine the need and eligibility for home care and respite care, SLPs can most certainly work to promote the latter three suggestions. Interventions targeted at increasing formal supports mirror the needs identified by caregivers of individuals with dysphagia due to head and neck cancer who report that few supports are available for carers, particularly after the cancer treatment itself has ended (Nund, Ward, et al., 2014). Further, beyond the need for strengthened social networks given that dysphagia forces many families to decrease meal-focused, social activities (Patterson et al., 2013; Penner et al., 2012), caregivers have also indicated being unprepared for how severe and long-lasting dysphagia can be, particularly when they are isolated from other individuals experiencing the same trajectory.

One study reviewed in the systematic review promoted social networks by providing telephone and letter support to caregivers so that they could still access services even if they could not physically attend (Harding & Higginson, 2003). The review suggests that while one-on-one support sessions with caregivers will help to educate and build problem-solving and coping skills, they are costly and time-consuming for both parties. Group interventions are commonly suggested as a method of delivering support and information, while allowing caregivers to meet others going through similar situations. Support groups allow caregivers to share experiences, which, in turn, may help the group members to develop self-help strategies based on others’ successes and failures. A study by Strozier (2012) evaluated the effectiveness of support groups in increasing social support for family caregivers and found that support
groups increase a feeling of social support for these caregivers and promote the use of other formal social supports. This may in turn reduce feelings of emotional burden.

Two systematic reviews have been conducted to explore information and support interventions specifically for caregivers of people with dementia (Thompson et al., 2007; Vandepitte et al., 2016). One of the reviews noted that only group interventions appear to positively impact depression in caregivers (Thompson et al., 2007). The most effective of these support groups were ones that were underpinned by psychoeducational theoretical foundations, whereby caregivers were guided to change their life outlook. The other review also found psychoeducational and cognitive behavioural therapy to be helpful, with multicomponent interventions yielding positive impacts on caregiver burden, self-efficacy, and burden (Vandepitte et al., 2016). However, results of this review suggested that individual interventions were most likely to be effective, allowing for the heterogeneity of different caregivers needs, expectations, and characteristics. Individual occupational therapy was also found to help by decreasing behavioural problems amongst patients and improving self-efficacy of caregivers. In yet another study, combination intervention that included counseling sessions in addition to mandatory participation in support groups was found to delay the need for care recipient nursing home placement (Mittelman et al., 1996). Institutionalization of patients with dementia was delayed by 329 days in the intervention group of caregivers, compared with the group of caregivers who did not receive any forms of support. These studies point to the need for an interdisciplinary approach to care, so multiple sources of burden can be addressed, and the need for social supports with individuals in similar situations. However, more research is
needed to determine the effectiveness of these groups specifically for caregivers of individuals with dysphagia and in order to determine optimal format and length.

Other suggestions for supporting caregivers include providing basic education on the management of swallowing impairments, given that many caregivers feel like they receive inadequate support and education on how to best manage their care recipient’s dysphagia (Mayre-Chilton et al., 2011; Penner et al., 2012). One reason for this may be that healthcare professionals have been found to assume that family caregivers are capable of carrying out their caregiving duties, so do not ask about what additional resources and information are required – or even if the caregivers feel like they can take on the responsibility (Glajchen, 2004). Yet, caregivers report a high and consistent need for information. Unfortunately, caregivers are often unsure how to effectively communicate or interact in the medical context, which has been found to be associated with needing information on how to reduce patient pain and distress, suggesting a negative impact on their ability to assist patients at home (Longacre et al., 2015). Another study found that the education clinicians do provide to caregivers tends to be highly medicalized and generic (Nund, Ward, et al., 2014). Therefore, it is critical that clinicians speak to both patients and caregivers in layman’s terms and avoid assuming that they do not want to know the details of the condition. In fact, research suggests that simply asking caregivers questions during medical interactions about how they are doing and tailoring communication to the caregiver can result in better information processing and caregiver engagement (Longacre et al., 2015). It may also be beneficial to help caregivers develop problem-focused strategies, whereby they confront issues and seek information themselves, further promoting increased self-efficacy. Research has shown that those who use emotion-
focused coping strategies tend to worry and deal with self-accusation, whereas those who take a problem-focused approach more appropriately confront issues and seek information (Forde & Pearlman, 1999). Research among caregivers of individuals with dementia has supported that caregiver self-efficacy for symptom management is an independent predictor of both caregiver burden and depression (Gallagher et al., 2011). Further, self-efficacy has been found to mediate the influence of patient neuropsychiatric symptoms on burden and depression among caregivers of patients with moderate to severe impairment.

Conclusions and Clinical Implications

In summary, as SLPs it is essential that we recognize that the consequences of dysphagia are not limited to the impairment itself and acknowledge dysphagia’s widespread impact on the entire family system. Informal family caregivers of individuals with dysphagia experience increased burden, which can negatively impact the health and well-being of both caregivers and our patients (Namasivayam-MacDonald & Shune, 2019; Shune & Namasivayam-MacDonald, 2020). We must find ways to maximize perceived support and self-efficacy for these caregivers. It may be helpful to organize caregiver support groups for caregivers of family members with similar medical diagnoses. It is also important that we do our best to educate our patients and their caregivers in ways that are understandable to them, providing them with resources to better understand the consequences of dysphagia and optimal management strategies. Most fundamentally, we must take the time to talk to our patients’ caregivers, asking how we can best help them carry out their caregiving role. When caregivers identify sources of stress, it is most helpful to identify feasible and tangible methods of reducing sources of burden or making the appropriate referrals to a social worker, counsellor or psychologist when the issue is
beyond our scope. As evidence-based clinicians, we must constantly evolve our practices based on research advancements and our growing knowledge base. It is clear that in order to best meet the needs of our patients with dysphagia we must also better meet the needs of their families and other informal caregivers.

References


review and meta-analysis. Commentary: When, where, and why do preventive home visits work? *BMJ, 323*(7315), 719. [https://doi.org/10.1136/bmj.323.7315.719](https://doi.org/10.1136/bmj.323.7315.719)


Harding, R., & Higginson, I. J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine, 17*(1), 63-74. [https://doi.org/10.1191/0269216302pm667oa](https://doi.org/10.1191/0269216302pm667oa)


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 International Publishing. [https://doi.org/10.1007/978-3-319-15877-8_578-1](https://doi.org/10.1007/978-3-319-15877-8_578-1)


**Figure Legends**

**Figure 1.** The cost of caregiving: The interdependent relationship between caregiver and care recipient physical health and well-being.

**Figure 2.** Application of the International Classification of Functioning, Disability, and Health framework (WHO, 2011) to understanding dysphagia as a chronic health condition that simultaneously impacts both care recipients and caregivers, based on the work of Nund and colleagues (2014; 2016).