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The influence of swallowing impairments as an independent risk factor for burden among caregivers of aging parents: A cross-sectional study

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Declaration of Conflicting Interests

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Abstract

Informal caregivers can experience high levels of burden, negatively impacting both the caregiver and care recipient. The presence of dysphagia (swallowing impairments) in care recipients is suggested to contribute to increased caregiver burden. The purpose of this study was to describe the type and severity of caregiver burden experienced by adults caring for community-dwelling older parents reporting symptoms of dysphagia. Using surveys from the National Health and Aging Trends Study and the National Study of Caregiving, data from 895 adults providing care for an aging parent were analyzed. Binary logistic regression analyses revealed that swallowing difficulties reported by a parent is a significant independent predictor of increased physical and emotional burden in their caregivers. Forty percent or more of these caregivers reported moderate to severe physical and/or emotional burden. Suggestions are provided to identify dysphagia early on and to provide supports for caregivers.

Keywords: Deglutition, dysphagia, National Health and Aging Trends Study, National Study on Caregiving, caregiver burden, older adults

Highlights

- The presence of swallowing difficulties in aging parents, the care recipients, is an independent predictor of increased emotional and physical caregiver burden among their adult children.
- The presence of swallowing difficulties in aging parents, the care recipients, is not a predictor of perceived financial caregiver burden among their children.
- Early identification and treatment of dysphagia in aging parents may be particularly crucial for improving caregiver burden.

Introduction

With a growing population of aging persons, it is important that we begin to consider methods of caring for older adults that allow them to maintain a high quality of life without inundating our healthcare system. One such option is supporting older adults to live at home despite the presence of medical conditions that may prevent them from being able to independently care for themselves. A meta-analysis designed to evaluate the effectiveness of home-based supports for older adults concluded that care recipients who resided at home had a significant reduction in mortality rates.¹ Other research has indicated that aging in place allows care recipients to maintain informal relationships and interactions, which strengthens ties to their communities and enhances well-being.^{2,3} Importantly, it also provides older adults with feelings of security and familiarity.⁴

This ultimately means that many older adults may end up relying on formal (i.e. paid) and/or informal (i.e. unpaid family and/or friends) caregivers to ensure that they are living at home safely and with the supports required to thrive. Increasingly, informal caregiving, particularly by working-age adults, has become a primary source of care provision for these older adults.⁵ It is estimated that 16.6% of adults in the United States provide informal caregiving to an adult, with 49% of these caregivers providing care for a parent or parent-in-law.⁶ With the growth in our aging population, these numbers are expected to continue to increase. Unfortunately, despite the known benefits for the care recipients associated with remaining in their homes, the burden of care placed on these informal caregivers, such as spouses and children, is often high. As a consequence of caregiver burden (i.e. the stresses that individuals experience due to providing care⁷), these family members often suffer from symptoms of depression and anxiety,^{8,9} and even decreased immunity.¹⁰ Caregivers are also less

likely to monitor their own health needs.^{8,9} Overall, caregivers of older adults in particular often experience higher levels of emotional, financial, and physical burden, negatively impacting both members of the caregiving dyad.^{11,12} Ultimately, the physical health and quality of life of caregivers and care recipients are interdependent,¹³ highlighting the necessity of including the needs of family caregivers within illness management models.

Research has shown that risk factors for caregiver burden related to the care context include female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress and lack of choice in being a caregiver.¹⁴ While many of these factors seem obvious and others unavoidable, it is important that we consider their implications in order to understand how to better support caregivers, when possible. To guide our understanding, it is essential to acknowledge that caregiver burden is not a single concept, but rather a multidimensional process.¹⁵ The multiple contributors to burden therefore can be interpreted within the guiding frameworks of stress theory (e.g., Pearlin's stress process model)¹⁶ and role theory (e.g., cognitive role theory),¹⁷ highlighting how these factors contribute to a caregiver's ability to adapt and cope. For example, whereas males are more likely to support care recipients only financially or in providing instrumental supports, females may carry more burden resulting from the stress and role overload associated with supporting care recipients emotionally while simultaneously assisting with a variety of physical daily tasks such as household chores, shopping and basic hygiene.^{15,18,19} Further role-related conflict can emerge as a result of lack of choice in being a caregiver. Additionally, if incompatibility arises among the expectations associated with the multiple roles an individual holds, such as employment, child rearing, and caregiving, role conflict can arise.¹⁷ Cohabitation of the care recipient and caregiver could be one indicator that a family member had no choice in becoming a caregiver.

This could also lead to less respite and more hours spent caregiving.²⁰ Cohabitation may also be related to a greater degree of care being provided, increased care recipient disability and greater financial responsibilities, three stressors that negatively influence caregivers' experiences of burden. These primary stress factors in turn can lead to the social isolation and depression that have been identified as both risk factors for and outcomes of caregiver burden.²¹

Interestingly, dysphagia (swallowing impairments) may also contribute to caregiver burden when the care recipient has a diagnosis of Parkinson's disease,²² motor neuron disease,²³ dementia,²⁴ stroke²⁵ and head and neck cancer.^{26,27} When their loved one suffered from swallowing difficulties, caregivers from these studies were relied upon for feeding, including dealing with tube-feeds, and spoke of loss of quality of life due to increased time and energy spent on extra and/or separate meal preparation.^{22-24,26,27} This also resulted in a disruption to family life when the family could not eat together, the care recipient took extra time to eat, the family could not go out to eat and/or the family felt uncomfortable having visitors over for meals.^{22,26} Both stress and role overload appear to contribute to caregiver burden. For example, caregivers have reported dramatically increased intentional activity and conscious thought required for meal preparation and increased fear and anxiety related to new eating-related responsibilities, feelings of being ill-prepared, concerns over adequate nutrition, and negotiating changing mealtime roles.²⁶⁻²⁹ A recent systematic review added to this literature by demonstrating that caregivers of community-dwelling older adults are also overwhelmed by care needs related to feeding and swallowing.³⁰ More specifically, spousal caregivers have been found to have a significant increase in emotional burden when swallowing was an issue for their community-dwelling care recipients over the age of 60.³¹ Of significance, swallowing impairments remained an independent predictor of emotional burden even when controlling for

other factors known to influence burden. This emotional burden experienced by caregivers of older adults with dysphagia parallels the anxiety, sadness and isolation previously noted by caregivers of other populations who experience dysphagia^{26,27,29,32} and is consistent with the outcomes suggested by stress theory and role theory.

While these findings contribute to a better understanding of what factors must be considered in developing supports for spousal caregivers, there are also many adults caring for community-dwelling older parents with swallowing impairments who also require our attention. Role theory and stress theory suggest that adult children caregivers, particularly female children, may actually be more vulnerable to burden. Adult children often have further responsibilities, such as taking care of their own families and employment, in addition to caring for their elderly parents. Thus, in addition to their normal roles and responsibilities, they are experiencing a non-normal role transition in which the parent is becoming dependent on the child. Some have referred to this group as the “sandwich generation”.³³⁻³⁶ This is meant to describe their dual responsibilities of caring for a parent and their own children³⁷ when they themselves are generally between the ages of 40 and 65.¹⁹ The increased stress and demands of caring for multiple generations at once put these caregivers at risk for a range of mental health problems, including depression and anxiety,³⁸ in addition to the likely physical and financial burden of caring for several people.

Despite the extensive research on caregiver burden, there is little work on the specific caregiver demands and burdens surrounding caring for a loved one with swallowing impairments. Moreover, it is unclear how swallowing impairments contribute to the caregiver burden shouldered specifically by children of older adults, who presumably have many responsibilities. The purpose of the current study was to elucidate the type and severity of

caregiver burden uniquely experienced by adults caring for aging parents with swallowing difficulties. More specifically, the study aimed to understand if the presence of self-reported dysphagia symptoms is an independent predictor of emotional, physical and/or financial burden for adult child caregivers. We hypothesized, based on role and stress theory and the previous literature, that these caregivers would suffer from emotional, physical and financial burden when their parent reported swallowing difficulties.

Methods

All data used in the current study were extracted from Round 1 of the National Health and Aging Trends Study (NHATS) and, its companion study, the National Study of Caregiving (NSOC), collected in 2011. Montaquila and colleagues³⁹ describe the sampling strategy and study design elsewhere; however, briefly, NHATS and NSOC are longitudinal studies of the health and aging of 8,245 Medicare health insurance recipients aged 65 and older and their caregivers, all living in the United States. The Medicare file represents 96% of the American, older adult population. Persons not represented are those born outside of the country who never qualified for benefits and those who are eligible but have not applied (e.g., delayed enrollment among those still employed). Data were collected through in-person interviews for which the baseline wave response rate was 71%. Only care recipients who also had corresponding responses from child caregivers were used in the present analyses. Excluded were persons living in nursing homes and other residential care environments, and those who did not have child caregivers and/or did not have corresponding caregiver data.

Complete data were available for 895 dyads. Gender, age, and education were extracted for all subjects, as well as race and ethnicity data for care recipients. Race and ethnicity data

were unavailable for caregivers. During the NHATS interviews, care recipients were asked if they had “any problems with chewing or swallowing while eating in the past month”, creating a dichotomous variable with a yes/no response that was used to determine swallowing status.

These individuals were also asked to rate their overall health and note any recent falls. In addition, they were asked if a doctor had diagnosed them with any chronic medical conditions, such as a heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia, and/or cancer. When possible, care recipients were asked about their memory, otherwise this information was obtained from a proxy.

The current study extracted NSOC data collected from adult caregivers that focused on their experience caring for a parent who participated in the NHATS survey. Caregivers were asked about the perceived difficulty of caregiving and if caring for their parent restricted their social and economic participation. They were also asked about their own general health, their employment status, how many hours per day that they helped their parent(s) and other caring responsibilities. Children were asked how often they helped their parent with personal care and mobility, how often their parent argued with them and how much other family members have disagreed over decisions related to the care of their parent. The caregivers were also asked if they felt appreciated, if they enjoyed spending time with their parent, if they felt lonely and depressed, if they felt like they had time for themselves and if they were able to handle their caregiving duties. In order to determine the type and severity of burden, caregivers were asked whether caregiving was financially, emotionally and/or physically difficult (dichotomous yes/no variable) and, if so, to rate the amount of difficulty on a Likert scale (1 = a little difficult, 5 = very difficult).

Statistical Analyses. Descriptive statistics were used to describe both the care recipients and caregivers. Binary logistic regression analyses were performed to examine the factors contributing to the burden experienced by caregivers and to determine if swallowing difficulties were an independent predictor of any type of burden when factors known to contribute to caregiver burden were controlled for. Three regression analyses were run; one to assess the predictors of physical burden on caregivers, a second to assess emotional burden and a third to assess financial burden. The same variables were included in each regression analysis, and they were selected and extracted for inclusion based on previous caregiver burden literature and *a priori* reasoning.^{14,31,40-46} The following variables were included: age, gender and general health of both caregivers and care recipients, care recipient medical diagnoses, care recipient memory status, care recipient fall status, measures of care recipient behavior and functional status/disability, caregiver education, caregiver workload and family conflict. Backward regression analysis methods were employed and the probability threshold for removal was set at 0.05. Severity of burden was only described for burden categories in which swallowing difficulties was a significant independent predictor based on the frequencies of each response option on the respective Likert scales. Chi-square statistics were then used to examine the proportion of care recipients reporting swallowing difficulties with the proportion of caregivers reporting feelings associated with burden (e.g., lonely and depressed). All analyses were performed using SPSS, version 22.0 (IBM Corp., Armonk, NY).

Results

<<insert Table 1 and 2 around here>>

Data describing the caregiver and care recipient characteristics are presented in Tables 1 and 2, respectively. The final caregiver sample included 895 adults caring for an aging parent. These caregivers were predominately middle-aged ($M = 54.1$, $SD = 8.9$) females ($n = 630$; 70.4%), who were in good overall health ($n = 719$; 81.2%). The mean age of their care recipients was 82.8 years ($SD = 7.8$) and the majority were also female ($n = 719$; 80.3%). A majority of caregivers were providing care to a parent who self-identified as Caucasian only ($n = 534$, 59.7%) and approximately one-third were providing care to a parent who self-identified as African American only ($n = 301$, 33.6%). The remaining care recipients self-identified as other/more than one race ($n = 46$, 5.1%), Asian only ($n = 5$, <1%) and American Indian only ($n = 3$, < 1%). Nearly 8% of care recipients identified as Hispanic ($n = 70$). Approximately 20% of caregivers were caring for a parent with reported swallowing difficulties ($n = 182$).

<<insert Table 3 around here>>

Results for the regression models for emotional, financial, and physical burden are presented in Tables 3, 4, and 5, respectively. The presence of self-reported swallowing difficulties was found to be associated with both emotional and physical burden, when controlling for other factors known to influence caregiver burden. The model for emotional burden explained 18% (Nagelkerke R^2) of the variance and correctly classified 66% of cases. Adults caring for aging parents with swallowing difficulties were 1.61 times more likely to experience emotional burden as compared to caregivers of parents without swallowing difficulties. Other factors found to increase the likelihood of experiencing emotional burden can be found in Table 3.

<<insert Table 4 around here>>

The model for physical burden explained 20% (Nagelkerke R^2) of the variance and correctly classified 79% of cases. The presence of self-reported swallowing difficulties was again associated with an increased likelihood of burden: adults caring for parents with symptoms of dysphagia were 1.71 times more likely to experience physical burden than adults caring for parents without symptoms of dysphagia. Table 4 displays all of the factors identified as being independent predictors of physical burden.

<<insert Table 5 around here>>

The model for financial burden explained 18% (Nagelkerke R^2) of the variance and correctly classified 78% of cases. Swallowing difficulties were not identified as a factor associated with an increased likelihood of experiencing financial burden; the factors found to increase the likelihood of experiencing financial burden can be seen in Table 5.

Given our purpose of elucidating both type and severity of caregiver burden uniquely experienced by those individuals caring for parents reporting symptoms of dysphagia, we further examined the degree of emotional and physical burden experienced by these caregivers. Of those children caring for a parent with swallowing difficulties experiencing emotional burden, 15% rated the burden as 1 (a little difficult), 20% as 2, 25% as 3, 21% as 4, and 19% as 5 (very difficult) as compared to 17% 1, 25% 2, 29% 3, 18% 4, and 11% 5 for children caring for a parent without swallowing difficulties experiencing emotional burden. Of the caregivers of care recipients with swallowing difficulties experiencing physical burden, 7% rated the burden as 1, 18% as 2, 23% as 3, 34% as 4, and 18% as 5 as compared to 22% 1, 23% 2, 31% 3, 14% 4, and 10% 5 for caregivers of care recipients without swallowing difficulties experiencing physical burden. Notably, the caregivers of parents with swallowing difficulties were also more likely to

report recent feelings of loneliness ($\chi^2(4) = 13.74, p = .008$) as compared to caregivers of parents without swallowing difficulties, with over 34% of the caregivers of parents with swallowing difficulties reporting feeling lonely at least some days as compared to 27% of caregivers of parents without swallowing difficulties.

Discussion

As our population ages, it is important that we consider comprehensive approaches to care that are sustainable and effective. These approaches must include ensuring that caregivers have the tools they need to support our patients to live comfortably at home for as long as possible and that the caregivers themselves feel supported. In order to facilitate this, the needs of informal caregivers should be identified and addressed. While it is complicated to identify specific areas where support is required for this group – possibly because they themselves have difficulty articulating what could ease their burdens^{47,48} – it is critical that researchers and clinicians work to unravel caregivers' common needs. As a means to begin this process, the current study sought to identify the type and severity of caregiver burden felt specifically by adult caregivers of aging parents who present with swallowing impairments. We found that this group of caregivers tends to suffer from both emotional and physical burden, but did not feel as much financial strain in the presence of swallowing difficulties. Of those individuals caring for parents with swallowing difficulties who reported emotional burden, 40% rated the burden as moderate to severe. We also found that just over 50% of individuals caring for parents with swallowing difficulties rated their physical burden as moderate to severe. Caregivers of parents with swallowing difficulties were also significantly more likely to report feeling lonely when compared to caregivers of parents who did not report any swallowing impairments.

The current study echoes the findings of previous caregiver burden literature suggesting that emotional stressors may be increased in the presence of dysphagia. A previous study focused on spouses of community-dwelling older adults with dysphagia reported that spouses only present with emotional burden, and not physical or financial burden, although the causes of this burden were unidentified.³¹ Sources of emotional burden may include caregiver guilt for eating whatever they please while their care recipient was on a restricted diet,^{22,28} fear of the care recipient choking and not knowing what to do if/when this occurred,²² the frustration involved in wanting care recipients to receive adequate nutrition despite swallowing difficulties,^{27,28} as well as social withdrawal^{22,23,26,49-53} and mealtime anxiety of the care recipient,^{49,51} which may extend to the caregiver. One study found that when care recipients became frustrated at meals, they offloaded this frustration on their family members.²² This all could result in the depression, psychological distress and anxiety that is often reported by caregivers of family with dysphagia.²³ Unfortunately, role overload can magnify these negative emotional responses as caregivers struggle to balance the eating-related needs associated with swallowing impairments, such as the preparation of multiple meals, the management of tube feedings and/or the increased amount of time and conscious thought given to meal-related activities.

While the current study was also unable to elucidate specific sources of physical burden, previous caregiver burden literature may provide some suggestions. One might assume that caring for multiple generations at once could be one source of this physical burden, as the average caregiver in the current study falls within the suggested age bracket of the sandwich generation (40 to 65 years old).¹⁹ However, only 18% of caregivers of parents with swallowing difficulties also had a child under the age of 18. Interestingly, 39% of caregivers who helped a parent with swallowing difficulties reported that they had other caregiving responsibilities in

addition to the care recipient included in the NHATS study. Therefore, it is possible that the physical burden being experienced is partly due to multiple responsibilities, including employment for 52% of caregivers. Previous literature has also suggested that when caring for people with dysphagia, physically-demanding stressors may include changes in family roles,^{23,26,27} supervision and/or providing assistance while eating,^{22,24,49} the need for separate meal preparation,^{22,26,28,49,54} the inability to eat outside of the home,^{22,26} forcing the care recipient to constantly prepare meals, and cleaning up after a meal with the food on the floor and/or on the care recipient.²² A review of the literature reported that many care recipients report physical exhaustion,²³ which is understandable given the aforementioned responsibilities in addition to the daily responsibilities of caregivers that are unrelated to the care recipient.

Similar to the previous study of spouses of community-dwelling older adults with dysphagia,³¹ the presence of swallowing difficulties did not independently increase the risk for financial burden among caregivers of aging parents. It is plausible to suggest that the costs associated with aging and age-related illnesses far outweigh the costs associated with swallowing difficulties. In other words, it is likely that these caregivers still experience financial burden, consistent with the previous literature, however this burden is not impacted by swallowing status. Previous research among caregivers of individuals with head and neck cancer similarly point to financial burden being less prevalent than physical and emotional burden (e.g., only one caregiver described financial burden of food wastage compared to the majority who described increased time and effort needed for meal preparation activities and decreased social interaction during meals).^{26,55} Unfortunately, the current study used a self-reported question on swallowing difficulties as the measure of “swallowing status,” which did not provide information on the type or severity of the swallowing difficulties. Therefore, it is also possible the subset of individuals

with difficulties swallowing requiring more costly nutrition-related interventions (e.g., tube feedings, thickened liquids) may not have been represented in the current sample.

It is clear that both stress and role overload specifically related to dysphagia can negatively impact the caregiving experience. These findings support that both negative stressors and the balancing of role responsibilities contribute to the complex nature of caregiver burden, as suggested by stress theory and role theory. In particular, the inter-relatedness between various care-context factors, including aspects related to both the caregiver and care recipient, is highlighted. Overall, dyadic health requires focused attention to be placed not only on the health and well-being of the care recipient, but also on the caregiver. For example, as demonstrated here, swallowing difficulties negatively contribute to the emotional and physical well-being of caregivers. The caregivers' feelings of anxiety, guilt, isolation and fear and increased time spent in meal-related tasks (e.g., preparation, supervision) may negatively impact the degree of care they are able to provide and negatively project onto the care recipient. These findings also contribute to the growing body of literature that supports dysphagia's unique role in increasing caregiver burden, a factor which previously has remained unexplored, particularly among older adults. Thus, improved family care for older adults necessitates a more intentional clinical and research focus on swallowing status.

Implications for Practice. In order to help mitigate the burden felt by caregivers of aging parents, it is important that healthcare professionals recognize the importance of attending to swallowing status and identify swallowing impairments early on. The best, and most systematic, method of doing this is to carry out a swallowing screening protocol at annual check-ups with a primary care physician after the age of 60. This is the age where much of the research has suggested that age-related changes to swallowing (also known as presbyphagia) begin.⁵⁶⁻⁶⁰

While presbyphagia alone does not generally signify disordered functioning, it can be compounded by disease and other medical conditions, resulting in dysphagia. A systematic review detailing the prevalence of dysphagia in community-dwelling older adults identified several risk factors for swallowing impairments including: a history of diagnosed clinical disease, being over the age of 70, cognitive decline and physical frailty.⁶¹ If changes in swallowing are recognized soon after a medical diagnosis is made, and/or when any of the other risk factors are present, then both the care recipient and caregiver can be better supported in making the necessary lifestyle changes to manage the dysphagia. Earlier identification and support, in turn, may help reduce the emotional and physical difficulties associated with dysphagia management, reducing dysphagia-specific burdens.

There are currently three dysphagia screening tools that have been validated amongst a group of healthy older adults and are applicable to the community-dwelling setting, all of which can be implemented by trained nursing assistants, nurses or other healthcare professionals: the Volume Viscosity Swallow Test (V-VST),⁶² the Sydney Swallowing Questionnaire (SSQ),⁶³ and the Eating Assessment Tool-10 (EAT-10).⁶⁴ As the name suggests, the V-VST involves swallow trials of varying viscosities and volumes beginning with 5, 10 and 20 mL trials of nectar thick liquid (also known as mildly thick liquids).^{62,65} There are various rules to follow if a patient is successful versus unsuccessful on any given trial, but a complete test would also include thin liquids and pudding thick liquids (also known as extremely thick liquids). Given the complexity of the test, it may not be the easiest to administer regularly. The SSQ involves asking 19 questions, 17 of which are answered via a visual analog scale.⁶³ This yields a score between 0 and 100 for each question, corresponding to the distance in millimeters from the origin of the visual analog scale. This test has also been validated in French⁶⁶ and Swedish.⁶⁷ Once again,

however, the complexity of scoring the test makes it impractical for quick administration and regular use. Finally, the EAT-10 is a ten-item questionnaire that has also been validated for use by a proxy.⁶⁴ Scoring is much simpler than the two previously described tests, as patients are asked to rate each of the ten statements on a scale from 0 to 4, where 0 indicates no problem and 4 indicates a severe problem. Some examples of statements include: “My swallowing problem has caused me to lose weight”, “Swallowing solids takes extra effort” and “I cough when I eat.” The responses to the questions can quickly be added together to produce a final score; a score greater than 3 indicates that a more comprehensive swallowing evaluation should be conducted. This questionnaire has also been validated in German,⁶⁸ Hebrew,⁶⁹ Greek,⁷⁰ Portuguese,⁷¹ Arabic,⁷² Italian,⁷³ Japanese,⁷⁴ Spanish,⁷⁵ Chinese⁷⁶ and Turkish.⁷⁷

Within a hospital setting, the 3-ounce water swallow test is a test with excellent sensitivity (96.4%) for identifying patients safe for oral intake.⁷⁸ Additionally, the test has been validated on people with a wide range of medical diagnoses, and can be quickly administered by a nurse by providing the patient with a cup filled with 3 ounces of water and asking them to drink without interruption. Criteria for test failure include: inability to drink the entire 3 ounces, coughing or choking up to one min after completion, and/or presence of post-swallow, wet-hoarse vocal quality. When considering ease of administration, the EAT-10 and 3-ounce water swallow test may be the optimal protocols to integrate within a regular health check-up.

In the case that a patient does not present with risk of dysphagia after a screening test has been administered, the patient and caregivers should be educated about the signs and symptoms of aspiration. A study by Logemann and colleagues found that a cough or throat clear, a gurgly voice and/or multiple swallows per bolus while eating or drinking are significantly associated with aspiration.⁷⁹ These signs can all be easily observed and reported to a healthcare professional

once a caregiver is primed to look for them. If a patient presents with risk of swallowing difficulty based on the results of a screening protocol, a referral should be made to a speech-language pathologist so that a more comprehensive swallowing evaluation can be performed to diagnose the dysphagia and better understand the impairments. Once an appropriate diet has been confirmed, the healthcare team, specifically speech-language pathologists and dietitians, can provide education to both the caregiver and care recipient on appropriate diet texture preparation using the International Dysphagia Diet Standardisation Initiative⁶⁵ as a guide. Increased education is crucial as research has supported that few caregivers feel like they receive sufficient support and/or preparation to deal with their care recipient's dysphagia.^{27,52} One study suggests that limited support may be provided due to the fact that many healthcare professionals assume – often incorrectly – that caregivers are fully capable of carrying out the necessary caregiver duties.⁸⁰ Caregivers often report that the information they do receive is highly medicalized and generic.²⁶ Further, families may not be aware of the role of the speech-language pathologist in managing the dysphagia, particularly when an individual's speech is not impaired.²⁶ In addition to the clinicians directly involved in the swallowing and nutrition aspects of care, social workers can also help arrange respite for families, as studies have found that respite is the single most important service that will enable caregivers to continue to provide care.^{23,24} Ultimately, a team approach to care is recommended to ensure successful at-home care. All caregivers desire to feel cared about by their medical providers and have unambiguous accountability on the part of their healthcare team in order to promote their own feelings of preparedness and capableness.⁸¹ To facilitate these outcomes, providers should be engaged in collaborative planning, anticipating patient and caregiver at-home needs, and providing actionable, relevant information to assist the process.

Limitations. A few limitations of the current study are important to note. This study used cross-sectional secondary data, which limits the ability to determine a causal relationship. It is also important to note that the data was collected in 2011 and is a compilation of self-reports rather than the use of formal tests to confirm diagnoses and other information. Further, the NHATS and NSOC surveys utilize a single question to determine presence/absence of swallowing difficulties and caregiver burden, and these terms were not defined or qualified for the participants. Additionally, information on variables such as caregiver race/ethnicity and co-residence status was either unavailable or too limited to be included in the analyses. However, despite these limitations associated with the databases themselves, the current study was able to meet the objectives of identifying whether swallowing difficulties were significantly associated with increased caregiver burden and identify the degree of burden associated with swallowing status. Future research would benefit from more in-depth, mixed-methods, longitudinal analyses of the relationship between care recipient swallowing status and caregiver burden, with a particular focus on identifying caregiver reported needs and malleable barriers to support. This would allow for the design of tailored, family-centered interventions that can mitigate the burden experienced by caregivers while maximizing clinical outcomes overall.

Conclusion

The present study significantly extends current knowledge about the family care of older adults by demonstrating the clear association between reports of swallowing impairments in community-dwelling older adults. It also confirms our hypotheses that adults caring for their parents shoulder physical and emotional burden; however, our hypothesis that these individuals also suffer from financial burden was refuted. Exact sources of burden are unidentifiable based

on the data collected, but previous research and concepts related to role theory and stress theory facilitate an initial understanding. The emotional burden may be caused by guilt and/or frustration, while the physical burden may be due to balancing multiple responsibilities. Regardless of the sources of burden, it is clear that the assessment of swallowing status should be integrated within regular health check-ups for community-dwelling older adults so that dysphagia can be identified as soon as possible, and education and supports can be provided to both the care recipient and caregiver by members of the multidisciplinary healthcare team. Ultimately, caregivers should also be seen as patients within a multidimensional approach to care in order to protect their health and safety, given their high risk for injury, poor health outcomes and adverse events. In turn, this will allow for a reduction in caregiver burden by teaching children how to become more competent, safe and supportive caregivers who are better able to protect and care for their parents. This will also help their parents, the care recipients, to maintain a high quality of life and level of functioning while residing at home.

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Declaration of Conflicting Interests

The authors declare they have no conflicts of interest to report.

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Table 1. Summary of caregiver (CG) data extracted from the NHATS database (Round 1) of adults caring for an aging parent.

CG Variables	All Caregivers n (%)	CGs of CRs with swallowing difficulties n (%)	CGs of CRs without swallowing difficulties n (%)
n	895	182 (20.3%)	713 (79.7%)
Age (years)	mean: 54.1±8.9 range: 19-77	mean: 53.4±9.3 range: 19-72	mean: 54.3±8.8 range: 23-77
Number of females	630 (70.4%)	119 (65.4%)	511 (71.7%)
Good overall health	719 (81.2%)	148 (81.8%)	571 (81.0%)
Children under 18 live with CG	167 (18.7%)	33 (18.1%)	134 (18.8%)
CG provides care to someone in addition to CR	368 (41.4%)	71 (39.0%)	297 (42.1%)
Ability to care for others impacted by care to CR	44 (5.0%)	11 (6.0%)	33 (4.7%)
Employed	446 (50.5%)	93 (51.6%)	353 (50.2%)
Hours working/week in job	36.6±12.2 range: 1-80	36.1±12.6 range: 1-77	36.8±12.1 range: 1-80
Hours per day spent caring for CR	mean: 4.6±4.7 range: 1-24	mean: 5.2±5.2 range: 1-24	mean: 4.4±4.5 range: 1-24
Helps CR with personal care	389 (43.5%)	88 (48.4%)	301 (42.2%)
Helps CR to get around	526 (58.8%)	117 (64.3%)	409 (57.4%)
Experience little time for themselves	459 (51.7%)	98 (53.8%)	361 (50.6%)
Feel lonely	268 (30.2%)	67 (36.8%)	201 (28.5%)
Feelings of depression	305 (34.5%)	75 (41.4%)	230 (32.7%)
Care is too much to handle	425 (47.7%)	93 (51.1%)	332 (46.8%)

CR argues with caregiver	572 (64.0%)	117 (64.3%)	455 (64.0%)
Family disagrees with details of care	205 (23.1%)	51 (28.3%)	154 (21.8%)
Experienced financial difficulties	238 (26.8%)	60 (33.3%)	178 (25.1%)
Experienced emotional difficulties	471 (53.0%)	110 (61.1%)	361 (51.0%)
Experienced physical difficulties	219 (24.7%)	57 (31.5%)	162 (22.9%)

Note: CR = care recipient

Table 2. Summary of care recipient (CR) data extracted from the NHATS database (Round 1) for older adults being cared for by an adult child.

CR Variables	All Care Recipients n (%)	CRs with swallowing difficulties n (%)	CRs without swallowing difficulties n (%)
n	895	182 (20.3%)	713 (79.7%)
Age (years)	mean: 82.8±7.8 years range: 65-103	mean: 82.8±8.1 range: 66-103	mean: 82.8±7.7 range: 65-102
Number of females	719 (80.3%)	140 (76.9%)	579 (81.2%)
Falls in past month	187 (20.9%)	50 (27.5%)	137 (19.2%)
Heart attack	201 (22.5%)	49 (26.9%)	152 (21.3%)
Heart disease	246 (27.5%)	60 (33.1%)	186 (26.1%)
High blood pressure	675 (75.6%)	136 (74.7%)	539 (75.8%)
Arthritis	654 (73.2%)	144 (79.1%)	510 (71.7%)
Osteoporosis	278 (31.2%)	74 (41.1%)	204 (28.7%)
Diabetes	315 (35.3%)	75 (41.2%)	240 (33.8%)
Lung disease	187 (20.9%)	59 (32.4%)	128 (18.0%)
Stroke	209 (23.4%)	52 (28.7%)	157 (22.1%)
Dementia	199 (22.3%)	52 (28.6%)	147 (20.7%)
Cancer	231 (25.8%)	63 (34.6%)	168 (23.6%)

Table 3. Determinants of emotional burden in caregivers based on logistic regression.

Variable	Parameter Estimate (95% Confidence Interval)	p-value
Care Recipient Dysphagia	1.61 (1.04-2.48)	.032
Care Recipient Osteoporosis	1.48 (1.02-2.14)	.039
Care Recipient Falls	1.86 (1.20-2.88)	.005
Caregiver Education		.027
<9 th Grade	a	
Some High School	1.08 (0.28-4.09)	.912
High School Diploma	2.23 (0.64-7.76)	.206
Vocational, Technical, Business, or Trade Certificate or Diploma	2.84 (0.75-10.82)	.126
Some College	2.18 (0.60-8.03)	.244
Associate's Degree	4.62 (1.11-19.20)	.035
Bachelor's, Master's, Professional, or Doctoral Degree	2.80 (0.80-9.79)	.108
Caregiver Hours Helps/Day	1.08 (1.03-1.13)	.001
Family Disagrees with Caregiver on Details of Care		<.001
Very Much	3.07 (1.53-6.16)	.002
Somewhat	2.36 (1.44-3.85)	.001
Not So Much	a	
Care Recipient Argues with Caregiver		<.001
A Lot	3.18 (1.51-6.71)	.002
Some	2.35 (1.46-3.79)	<.001
A Little	1.37 (0.93-2.01)	.115
Not At All	a	

^a Referent category.

Table 4. Determinants of physical burden in caregivers based on logistic regression.

Variable	Parameter Estimate (95% Confidence Interval)	p-value
Care Recipient Dysphagia	1.71 (1.04-2.81)	.035
Care Recipient Heart Attack	0.57 (0.33-1.00)	.048
Care Recipient Heart Disease	1.60 (1.01-2.56)	.047
Caregiver Gender, Female	1.61 (1.00-2.60)	.050
Caregiver Health		<.001
Excellent	0.13 (0.04-0.45)	.001
Very Good	0.15 (0.05-0.50)	.002
Good	0.27 (0.08-0.89)	.031
Fair	0.61 (0.18-2.05)	.425
Poor	^a	
Caregiver Helps Care Recipient with Personal Care		.005
Every Day	3.18 (1.67-6.04)	<.001
Most Days	2.51 (1.19-5.29)	.016
Some Days	1.48 (0.84-2.63)	.175
Rarely	1.62 (0.88-2.98)	.125
Never	^a	
Family Disagrees with Caregiver on Details of Care		<.001
Very Much	3.87 (1.98-7.59)	<.001
Somewhat	1.63 (0.94-2.83)	.084
Not So Much	^a	

^a Referent category.

Table 5. Determinants of financial burden in caregivers based on logistic regression.

Variable	Parameter Estimate (95% Confidence Interval)	p-value
Caregiver Age	0.98 (0.96-1.0)	.044
Caregiver Health		.015
Excellent Health	0.19 (0.05-0.64)	.008
Very Good	0.19 (0.06-0.64)	.007
Good	0.32 (0.10-1.05)	.061
Fair	0.34 (0.10-1.16)	.086
Poor	^a	
Caregiver Helps Care Recipient Get Around		<.001
Everyday	2.60 (1.25-5.44)	.011
Most Days	3.69 (1.91-7.13)	<.001
Some Days	1.79 (1.02-3.15)	.044
Rarely	0.88 (0.44-1.78)	.728
Never	^a	
Family Disagrees with Caregiver on Details of Care		.011
Very Much	1.70 (0.87-3.35)	.123
Somewhat	2.08 (1.25-3.47)	.005
Not So Much	^a	
Care Recipient Argues with Caregiver		.007
A Lot	2.68 (1.28-5.62)	.009
Some	2.07 (1.21-3.53)	.008
A Little	1.14 (0.70-1.87)	.605
Not At All	^a	

^a Referent category.