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Swallowing Impairments Increase Emotional Burden in Spousal Caregivers of Older Adults

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Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

Research Ethics and Patient Consent

The study procedure for the National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) were approved by the Johns Hopkins Bloomberg School of Public Health's Institutional Review Board (IRB). Given the public accessibility of the NHATS and NSOC databases, further IRB approval was not required.

Abstract

Objective: To determine the type and extent of caregiver burden uniquely experienced by spousal caregivers of older adults with dysphagia. **Method:** Using the Round 1 surveys from the National Health and Aging Trends Study and the National Study of Caregiving, we analyzed data on 422 community-dwelling older adults and their spousal caregivers. **Results:** Approximately 17% of care recipients reported swallowing difficulties. Logistic regression analysis revealed that caregivers of spouses with dysphagia were significantly more likely to experience emotional burden ($p = .038$; OR = 2.06; 95% CI: 1.04-4.09). Of those spouses caring for partners with dysphagia who reported emotional burden, nearly 70% rated the burden moderate to severe. **Discussion:** Dysphagia in community-dwelling older adults is associated with increased emotional burden among spousal caregivers. Given the intricate relationship between the health and wellbeing of both members of the caregiving dyad, these findings support the need for interventions that prioritize dyadic health.

Keywords: Dysphagia; Deglutition; Caregiver Burden; Family Caregiving; National Health and Aging Trends Study

Introduction

It is estimated that up to 35% of otherwise healthy older adults experience swallowing difficulties (dysphagia), with prevalence dramatically increasing with advanced age and a variety of age-related health conditions, such as stroke and dementia (Cabre et al., 2014; Howden, 2004; Martino et al., 2005; Ney, Weiss, Kind, & Robbins, 2009; Ortega, Martin, & Clave, 2017; Roy, Stemple, Merrill, & Thomas, 2007; Siebens et al., 1986). Unfortunately, dysphagia's biopsychosocial impacts are profound, ultimately leading to reduced quality of life and increased mortality (Altman, Yu, & Schaefer, 2010; Karvonen-Gutierrez et al., 2008; Klinke, Wilson, Hafsteinsdottir, & Jonsdottir, 2013; Nguyen et al., 2005; Patel et al., 2018; Shune, Karnell, Karnell, Van Daele, & Funk, 2012). Given the high health and economic burden dysphagia has on the individual and the healthcare system (Patel et al., 2018), efforts to prioritize early assessment and evidence-based rehabilitative practices are growing (Easterling, 2017; Leder, Suiter, Agogo, & Cooney, 2016; Ortega et al., 2017).

Unfortunately, impairment-level approaches fail to recognize the substantial influence a chronic condition has on the larger family system, including spousal caregivers (Rolland, 1994). A recent systematic review identified the presence of increased burden among **family** caregivers of community-dwelling older adults with dysphagia (blinded for peer review). **Specifically, self-reported swallowing difficulties, worsening feeding behaviors over time, and the use of feeding tubes were all associated with increased general burden in caregivers. Emotional and psychological burden related to concerns over nutritional intake, the balance between choking risks and the benefits of eating desired foods, and the grieving/acceptance process over feeding tube use also emerged.** However, given the paucity of articles describing the

impact of dysphagia on caregiver burden and the divergence of methods used to measure burden, the prevalence and types of burden were not identified.

Previous research on third-party disability related to head and neck cancer has suggested that dysphagia leads to widespread activity limitations and participation restrictions among caregivers (Nund et al., 2016). Caregivers of individuals with head and neck cancer, stroke, and other neurological disorders have reported that dysphagia results in increased fear, anxiety, sadness, guilt, and isolation, decreased support and social involvement outside of the home, and poorer quality of life overall (Arslan, Demir, & Karaduman, 2017; Johansson & Johansson, 2009; Nund et al., 2016; Nund et al., 2014; Patterson, Rapley, Carding, Wilson, & McColl, 2013; Penner, McClement, Lobchuk, & Daeninck, 2012). **Commonly reported caregiver fears and anxiety across all studies related to both caregiver (e.g., sudden increased caregiving responsibility, feelings of being ill-prepared, negotiating changing roles) and care recipient (e.g., coughing/choking, adequate nutrition). The dramatic shift in typical daily routines, from the rigidity of tube feeding schedules, to the increase in conscious thought and intentional activity required for meal preparation, and the decrease in social involvement outside of the home as related to changed eating routines, starkly contrasted with the previous lives of these caregivers. Overall, the important social, togetherness aspects of mealtimes became dramatically reduced: caregivers and other family members reported eating alone or in secret stemming from feelings of guilt and discomfort.** Of interest, the mental functions domain was the only impairment-level component of the International Classification of Functioning, Disability and Health that appeared to be influenced (Nund et al., 2016). Further, only one caregiver of an individual with head and neck cancer described financial burden of food wastage, despite many caregivers describing increased domestic efforts related to

meal preparation such as shopping for and cooking the meals (Nund et al., 2016; Nund et al., 2014). **Taken together, these results suggest a model of the physiologic (e.g., increased risk for aspiration, requirements for modified foods and/or tube feedings, nutritional needs) and psychosocial (e.g., decreased shared meals, decreased social participation) changes associated with dysphagia as leading to increased emotional burden among caregivers of individuals with dysphagia.** Thus, dysphagia may play a unique role particularly in increasing the emotional burden experienced by caregivers of older adults, but this has yet to be documented in literature.

Our healthcare system relies on the efforts of informal caregivers, especially as our aging population continues to grow (He, Goodkind, & Kowal, 2016). Yet, these caregivers of older adults experience higher levels of emotional, financial, and physical difficulties, which can negatively impact both the caregiver and the care recipient (Torti, Gwyther, Reed, Friedman, & Schulman, 2004; Wolff, Spillman, Freedman, & Kasper, 2016). Therefore, this model **of care** is not sustainable **as currently practiced**: informal caregivers are not only members of the support team; they are individuals with their own needs. Prior to intervening, we must first recognize the factors that contribute to their overall levels of burden and better understand how these factors increase burden. Dysphagia has been found to be related to caregiver burden across a variety of populations (**Johansson & Johansson, 2009; Nund et al., 2016; Nund et al., 2014; Patterson et al., 2013; Penner et al., 2012**). Yet, in light of the multitude of factors that can also contribute to such burden, it remains unclear what dysphagia's independent role is in increasing the likelihood of burden in caregivers of older adults. The objectives of the current study were to determine the type and extent of caregiver burden uniquely experienced by spouses of

community-dwelling older adults with dysphagia.

Methods

Data Sources and Study Cohort

Data in the present study were extracted from two linked population-based surveys: the National Health and Aging Trends Study (NHATS) and, its companion study, the National Study of Caregiving (NSOC) (NHATS, 2011). Details of the sampling strategy and design are described elsewhere (Montaquila, Freedman, Edwards, & Kasper, 2012). In brief, NHATS and NSOC are nationally representative longitudinal studies of the health and wellbeing of 8,245 Medicare recipients aged 65 and older and their caregivers. The study procedure was approved by the [blinded for peer review] Institutional Review Board. NHATS and NSOC were designed to guide efforts to reduce disability, maximize health and independent functioning, and enhance quality of life for older adults and their caregivers. In-person interviews were used to collect data on the physical, social, technological and service environment, physical and cognitive capacity, use of assistive devices and rehabilitation, help received with daily activities (self-care, household, and medical), participation in valued activities, and wellbeing of both care recipients and their caregivers.

Data for the current cross-sectional study were extracted from the first round of NHATS and NSOC interviews that occurred in 2011 and focuses solely on community-dwelling care recipient-spouse dyads. Care recipients were excluded if they lived in nursing homes or assisted living facilities and/or if a cohabitating spousal caregiver was not interviewed. Complete data was available for 422 dyads. Basic demographic information, such as gender, age, and education, was extracted for all subjects. Race and ethnicity data were also available for care recipients.

Within the NHATS interviews, presence of swallowing difficulties was determined by asking care recipients if they had “any problems with chewing or swallowing while eating in the past month”. Care recipients were also asked to rate their overall health and to indicate if a doctor had diagnosed them with any of the following chronic medical conditions: heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia, and/or cancer. Information about memory was obtained from either the care recipient or a proxy, as appropriate. Breathing difficulties and falls status were also reported.

For the purposes of the current study, NSOC data collected from caregivers focused on their caregiving experience, including perceived difficulty and restrictions on social participation. They were asked about their general health, the number of hours per day that they helped their spouse, and the number of years they have acted as a caregiver. Caregivers were asked about the help they provided, such as how often they helped their spouse with personal care or getting around, and potential conflict resulting from their caregiving, such as how often their spouse argued with them and how much other family has disagreed over the details of the care provided. Questions were also asked about feeling appreciated, enjoyment when spending time with their spouse, feelings of loneliness and depression, time for themselves, and if caregiving was more than they could handle. In order to determine presence of financial, emotional, and/or physical burden, caregivers were asked whether caregiving was financially, emotionally, and/or physically difficult 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. More specifically, we explored whether swallowing status was an independent predictor of financial, emotional, and/or physical burden, when controlling for other factors known to contribute to caregiver burden. Variables were selected for inclusion in the analysis based on the previous literature and *a priori* reasoning (e.g., Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Huang, Lee, Liao, Wang, & Lai, 2012; Juntunen et al., 2018; Limpawattana, Theeranut, Chindaprasirt, Sawanyawisuth, & Pimporm, 2013; Neufeld & Harrison, 2003; Pratt, Schmall, Wright, & Cleland, 1985; Rinaldi et al., 2005; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006; Springate & Tremont, 2013).

Variables examined in the current study **for all models** included: age, gender, and health status of caregivers and care recipients, caregiver education, care recipient **medical** diagnoses, care recipient memory status, care recipient fall status, measures of care recipient behavior and functional status/disability, caregiver workload, and family conflict. Backward regression analysis methods were utilized and the probability threshold for removal was set at 0.05. Extent of burden was described only for burden categories in which dysphagia was a significant independent predictor by analyzing the frequencies of each response option on the respective Likert scales. Chi-square statistics were also used to examine the proportion of care recipients reporting swallowing difficulties with the proportion of caregivers reporting feelings associated with burden (e.g., no time to themselves). All analyses were performed using SPSS (Version 22, IBM Corporation, Armonk, NY).

Results

Data describing the care recipients and caregivers are summarized in Tables 1 and 2, respectively. This was a large and diverse sample of 422 care recipient-spouse dyads from across the United States. The mean age of the care recipients was 77.3 ± 7.5 years (range: 65-98 years; 249 male) and the mean age of caregivers was 73.5 ± 9.1 years (range: 42-95 years; 250 female). The average couple had lived together for 42.6 years. Data on race and ethnicity was available only for care recipients. The majority of participants identified as Caucasian ($n = 333$; 79%), 86 (20%) identified as Hispanic, 80 (19%) identified as African American, 14 (3%) identified as American Indian, and 4 (<1%) identified as Asian. Of the 422 care recipients included in the current study, 72 (17%) self-reported swallowing difficulties. There were also 58 (14%) care recipients who reported difficulty eating by themselves without help and 67 (16%) who received help eating.

<<insert Table 1 around here>>

As can be seen in Table 2, caregivers reported helping their spouses for, on average, 4.4 ± 5.3 hours per day. Nearly half of caregivers reported helping their spouses with personal care ($n = 263$; 62%) and more than half reported helping their spouses get around ($n = 270$; 64%). One hundred and seventy-one (41%) caregivers reported feeling that the care they were providing was too much to handle and 117 (28%) reported that they had little time for themselves. Loneliness was reported by 105 (25%) caregivers and feelings of depression were reported by 137 (32%) caregivers. A majority of caregivers indicated that their spouses argue with them ($n = 294$; 70%), although only 40 stated that they argue a lot (10%). Financial

difficulties arising from caring for their spouse were reported by 102 (24%) caregivers, physical difficulties by 141 (33%) caregivers, and emotional difficulties by 192 (45%) caregivers.

<<insert Table 2 around here>>

Results for the regression models for emotional, financial, and physical burden are presented in Tables 3, 4, and 5, respectively. Dysphagia was only found to be associated with emotional burden, when controlling for other factors known to influence caregiver burden. The model for emotional burden explained 32% (Nagelkerke R^2) of the variance and correctly classified 72% of cases. Caregivers of spouses with dysphagia were 2.06 times more likely to experience emotional burden than caregivers of spouses without dysphagia. Being a female caregiver and having a higher education was also associated with an increased likelihood of experiencing emotional burden, while better care recipient memory capabilities was associated with decreased burden. Other factors found to influence emotional burden included: caregiver health (“fair” health as compared to “poor” increased risk of burden), helping care recipients with personal care (helping “some days” or “rarely” as compared to “never” increased burden), and care recipient and caregiver arguing (care recipient arguing “some” as compared to “not at all” increased burden).

<<insert Table 3 around here>>

The model for financial burden explained 26% (Nagelkerke R^2) of the variance and correctly classified 75% of cases. Factors associated with an increased likelihood of experiencing financial burden included care recipient diabetes, care recipient dementia, caregiver helping care recipient to get around, care recipient and caregiver arguing, and family disagreeing with caregiver care choices. Increasing caregiver age was associated with a reduction in the likelihood of experiencing financial burden. The model for physical burden explained 31% (Nagelkerke R^2)

of the variance and correctly classified 56% of cases. Factors associated with an increased likelihood of experiencing physical burden included care recipient heart disease, care recipient lung disease, care recipient dementia, poor caregiver health, and caregiver helping care recipient to get around.

<<insert Tables 4 and 5 around here>>

Given that dysphagia was significantly associated only with increased emotional burden, additional analyses explored aspects of extent of emotional burden in this subgroup. Caregivers of older adults with swallowing difficulties were more likely to report that they had little time to themselves ($\chi^2(2) = 15.47, p < 0.001$) and recent feelings of depression or hopelessness ($\chi^2(3) = 21.57, p < 0.001$) as compared to caregivers of spouses without dysphagia. Fewer spouses of partners with dysphagia reported minimal to no impact of caregiving on time to themselves (40%) as compared to spouses of partners without dysphagia (65%). Approximately 45% of spouses caring for a partner with dysphagia reported that they had only some time for themselves and 15% reported very little time for themselves, **compared to 24% and 11% for caregivers of partners without dysphagia**. Similarly, nearly 44% of spouses caring for a partner with dysphagia reported that they felt down, depressed, or hopeless several days over the previous month and 8% reported feeling down, depressed, or hopeless for more than half of the previous month, **compared to 19% and 10% for caregiver of partners without dysphagia**. Overall, of the caregivers of care recipients with dysphagia **experiencing emotional burden**, 11% rated the **burden** as 1 (a little difficult), 20% as 2, 46% as 3, 16% as 4 and 7% as 5 (very difficult) **as compared to 25% 1, 20% 2, 21% 3, 18% 4, and 16% 5 for caregivers of partners without dysphagia experiencing emotional burden**.

Discussion

The objectives of the current study were to determine the type and extent of burden uniquely experienced by spousal caregivers of older adults with dysphagia. Results indicate that, as compared to caregivers of older adults without dysphagia, spousal caregivers of individuals with dysphagia are more likely to experience emotional burden, even when controlling for other factors known to influence caregiver burden. Of those spouses caring for partners with dysphagia who reported emotional burden, nearly 70% rated the burden as moderate to severe. Further, these caregivers often reported feeling depressed, with over 50% having felt depressed or hopeless at least several days in the month prior to being interviewed. Many also felt as though they had little time to themselves, with nearly 60% indicating that caregiving at least somewhat impacted their personal time.

These findings contribute to the growing literature base describing the impact of dysphagia on caregivers and provide a more detailed description of the burden uniquely experienced by spousal caregivers of community-dwelling older adults. While previous research has indicated that these caregivers experience dysphagia-related burden, the exact nature of the burden and underlying contributors has remained unclear (blinded for peer review). Based on the current results, caregivers of older adults report increased emotional burden that is significantly associated with the presence of dysphagia in their care recipients. Such burden is consistent with the anxiety, sadness, and isolation previously noted in caregivers of individuals with head and neck cancer, stroke, and other neurological diseases who experience dysphagia (Arslan et al., 2017; Johansson & Johansson, 2009; Nund et al., 2016; Nund et al., 2014; Patterson et al., 2013; Penner et al., 2012). These emotional responses are likely related, in part, to the widespread

activity limitations and participation restrictions described by these caregivers, including decreased social involvement outside of the home, and overall feelings of decreased support. The spousal caregivers of older adults with dysphagia in the current study also indicated having decreased time to themselves. Dysphagia-related meal preparation, such as changes in shopping patterns to accommodate special diets and cooking multiple family meals, markedly increases required domestic efforts (Nund et al., 2016; Nund et al., 2014). Further, nutritional intake needs dramatically shift daily routines, increasing schedule rigidity. Thus, dysphagia-related mealtime activities may be extremely time consuming for caregivers.

Of interest, almost none of the participants indicated feeling underappreciated by their care recipient and nearly all still enjoyed spending time with their spouse. Mealtimes are a profoundly social experience and a key component of the normality of daily life. The disruptions in this process stemming from dysphagia could fundamentally alter the intimate relationship between spouses. Yet, this did not appear to be the case. While caregivers reported a negative influence of dysphagia on individual-level factors (e.g., depression, time to self), the more relational variables, such as mutual appreciation and enjoyment of time spent together, did not appear to be negatively influenced. Such findings echo previously revealed sentiments regarding a lack of a detrimental effect of dysphagia on partner relationships (Nund et al., 2014). In fact, caregivers have previously reported an intentional emphasis on the socialization aspects of mealtimes, stating that this was a more important issue than the “actual food” (Johansson & Johansson, 2009).

It is important to recognize that individual-level **health** factors are less meaningful in isolation, as they can ultimately influence the wellbeing of both members of the caregiving dyad – and, importantly, how the dyad manages the health condition together (Lyons & Lee, 2018).

This is due to the fact that the physical health and quality of life of both the caregiver and care recipient are interdependent (Lyons & Lee, 2018; Pucciarelli et al., 2017). For example, among older adults, spousal depression increases the risk for lower cognitive functioning and may also increase the risk for depression in the other spouse (Monin et al., 2018). Not surprisingly, aspects of caregiver depression and wellbeing, such as sadness and fatigue, are **also** associated with higher care recipient healthcare expenditures among older adults (Ankuda et al., 2017). Our results support that individual-level care recipient and caregiver variables, **such as care recipient memory and caregiver gender**, as well as relational factors, **such as quality of communication between members of the dyad**, contribute to overall caregiver burden. Importantly, our results also suggest that dysphagia status, a previously unexplored and uncontrolled for care recipient factor, further contributes to increased emotional burden in caregivers of older adults. **These findings continue to highlight the interdependent nature of dyadic health. However**, continued investigation into the multidirectional relationship between caregiver and care recipient health among older adults given the presence of dysphagia is needed.

For spousal caregivers of older adults in particular, the line between caregiver and care recipient may not be entirely clear as they themselves are also aging and present with their own healthcare needs (Pinquart & Sorensen, 2011). Caregivers of spouses with an activity of daily living impairment, such as dysphagia, are more likely to not get enough rest, not have enough time to exercise, not have time to recuperate from illness, and forget to take prescription medications, compared with non-caregivers (Burton, Newsom, Schulz, Hirsch, & German, 1997). The consequence of this negligence of their own health could result in an eventual inability to take care of their loved ones, which would further inundate an already over-crowded

healthcare system. Moreover, emotional burden has been shown to be an independent risk factor for mortality amongst elderly spousal caregivers (Schulz & Beach, 1999). Thus, the ultimate, **longitudinal** impact of dysphagia on the spousal caregiving dyad over time warrants further investigation. **Further, given the association between the presence of dysphagia and increased emotional burden, it is important to further delineate what caregiver-, care recipient-, and dyad-related variables may be moderating this relationship and contributing to differences in levels of perceived burden.** We must determine feasible and effective methods of supporting spousal caregivers of community-dwelling older adults with dysphagia before their feelings of burden exceed what they are able to handle.

Limitations

Although the objectives of the current study were met, there were some unavoidable limitations. Firstly, we relied on a single question for determining dysphagia status **and presence/absence of burden**. While **dysphagia** prevalence was within the range of what would be expected from community-dwelling older adults, it may be a bit lower than expected for a population of individuals with chronic conditions. Moreover, dysphagia status, **burden**, and other health information for both care recipients and caregivers was determined by self-reporting, which is a widely used method of collecting information regarding individuals' health status (Bhandari & Wagner, 2006). However, there is little known about their accuracy in regards to specific health issues, and previous research investigating the relationship between subjective and objective assessments of dysphagia in patients with various diagnoses, **for example**, has yielded conflicting results (Ding & Logemann, 2008; Horner & Massey, 1988; Lazarescu et al., 2010; Pauloski et al., 2002). Additionally, race and ethnicity data was not known for caregivers, but is

known to influence the caregiving experience (Kim et al., 2018; Namkung, Greenberg, & Mailick, 2017), warranting further investigation. **This study employed cross-sectional data, which limits the ability to establish a cause and effect relationship. Additionally, the generated models did not account for possible interactions between the included variables as the purpose of this initial study was to first establish whether dysphagia itself uniquely contributes to burden experienced by caregivers.**

Conclusion

Spousal caregivers of community-dwelling older adults with dysphagia experienced greater emotional burden than caregivers of spouses without dysphagia. These findings support that the third-party disability experienced by caregivers of individuals with dysphagia is a consequence, at least in part, of the presence of dysphagia itself. Such third-party disability, in turn, can also negatively influence the health and wellbeing of the care recipient with dysphagia. **It is crucial that future research targets a more in-depth exploration of this multidirectional relationship between caregiver, care recipient, and dyadic health in the presence of dysphagia longitudinally, identifying potential moderators of this relationship and targets for therapeutic intervention.**

This study adds to the growing literature base not only of the impact of dysphagia on caregivers, but also of chronic illness on caregivers more broadly. Concerted efforts are required to transition our management models from solely impairment-based toward more comprehensive approaches to care that situate illness in the context within which it occurs. Given that the health and wellbeing of both members of the caregiving dyad are intricately linked, it is important to not only look at how care recipient variables influence the caregiver and how caregiver variables

influence the care recipient, but also how the health of the dyad is influenced by these variables and changes over time. As our reliance on informal caregivers continues to grow and as the age of our caregiving dyads continues to increase, it is essential to prioritize dyadic health.

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Legends/Table Titles

Table 1. Summary of care recipient (CR) data extracted from the NHATS database.

Table 2. Summary of caregiver (CG) data extracted from the NSOC database.

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

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

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

Table 1. Summary of care recipient (CR) data extracted from the NHATS database. Variables that significantly differed between the two groups are indicated with superscript numbers.

CR Variables	All Care Recipients n (%)	CRs with dysphagia n (%)	CRs without dysphagia n (%)
n	422	72	350
Age (years)	mean: 77.3±7.5 years range: 65-98	mean: 76.7±7.6 range: 66-98	mean: 77.4±7.5 range: 65-95
Number of males	249 (59%)	48 (67%)	201 (57%)
Years married to CG	mean: 42.6±18.7 range: 0-72	mean: 41.2±18.3 range: 4-69	mean: 43.0±18.6 range: 0-72
Swallowing difficulties	72 (17%)	72 (100%)	0 (0%)
Difficulty eating by themselves without help	58 (14%)	24 (33%) ¹	34 (10%)
Received help eating	67 (16%)	20 (28%) ²	47 (13%)
Falls in past month	85 (20%)	17 (23%)	68 (19%)
Heart attack	86 (20%)	22 (31%)	64 (18%)
Heart disease	113 (27%)	27 (38%) ³	86 (25%)
High blood pressure	299 (71%)	53 (74%)	246 (70%)
Arthritis	278 (66%)	54 (75%)	224 (64%)
Osteoporosis	91 (22%)	20 (28%)	71 (20%)
Diabetes	150 (36%)	36 (50%) ⁴	114 (33%)
Lung disease	87 (21%)	23 (32%) ⁵	64 (18%)
Stroke	95 (23%)	27 (38%) ⁶	68 (19%)
Dementia	72 (17%)	13 (18%)	59 (17%)
Cancer	139 (33%)	31 (43%) ⁷	108 (31%)
Difficulties breathing	125 (30%)	37 (51%) ⁸	88 (25%)

¹ $\chi^2(1) = 9.51, p = 0.002$

⁴ $\chi^2(1) = 7.92, p = 0.005$

⁷ $\chi^2(1) = 4.02, p = 0.045$

² $\chi^2(2) = 35.20, p < 0.001$

⁵ $\chi^2(1) = 6.81, p = 0.009$

⁸ $\chi^2(1) = 19.73, p < 0.001$

³ $\chi^2(1) = 5.09, p = 0.024$

⁶ $\chi^2(1) = 11.18, p = 0.001$

Table 2. Summary of caregiver (CG) data extracted from the NSOC database. Variables that significantly differed between the two groups are indicated with superscript numbers.

CG Variables	All Caregivers n (%)	CGs of CRs with dysphagia n (%)	CGs of CRs without dysphagia n (%)
n	422	72	350
Age (years)	mean: 73.5±9.1 range: 42-95	mean: 72.3±8.5 range: 52-95	mean: 74.2±9.2 range: 42-95
Number of females	250 (59%)	48 (67%)	202 (58%)
Good overall health	262 (66%)	45 (63%)	217 (62%)
Felt unappreciated	8 (2%)	1 (1%)	7 (2%)
Spouse argues with caregiver	294 (70%)	54 (75%)	240 (70%)
Did not enjoy spending time with spouse	2 (<1%)	0 (0%)	2 (<1%)
Little time for themselves	117 (28%)	43 (60%) ¹	74 (21%)
Felt lonely	105 (25%)	25 (35%)	80 (23%)
Feelings of depression	137 (32%)	37 (51%) ²	100 (29%)
Care was too much to handle	171 (41%)	34 (47%)	137 (39%)
Family disagrees with details of care	53 (13%)	14 (19%)	39 (11%)
Hours per day spent caring for CR	mean: 4.4±5.3 range: 1-24	mean: 5.7±6.4 range: 1-24	mean: 4.1±4.9 range: 1-24
Years spent caring for CR	mean: 12.0±16.1 range: 0-70	mean: 10.5±14.5 range: 1-69	mean: 11.8±16.5 range: 0-70
Helps spouse with personal care	263 (62%)	53 (73%)	210 (60%)
Helps spouse to get around	270 (64%)	51 (71%)	219 (62%)
Experienced financial difficulties	102 (24%)	18 (25%)	84 (24%)

Experienced physical difficulties	141 (33%)	31 (43%)	110 (31%)
Experienced emotional difficulties	192 (45%)	44 (61%) ³	148 (42%)

¹ $\chi^2(2) = 15.47, p < 0.001$

² $\chi^2(3) = 21.57, p < 0.001$

³ $\chi^2(1) = 8.74, p = 0.003$

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

Variable	Parameter Estimate (95% Confidence Interval)	p-value
Care Recipient Dysphagia	2.06 (1.04-4.09)	.038
Care Recipient Memory Status		.025
Excellent	0.34 (0.11-1.02)	.054
Very Good	0.28 (0.11-0.71)	.008
Good	0.32 (0.14-0.76)	.009
Fair	0.62 (0.25-1.53)	.303
Poor	a	
Caregiver Gender, Female	2.39 (1.40-4.10)	.002
Caregiver Education		.002
<9th Grade	a	
Some High School	2.44 (0.73-8.14)	.146
High School Diploma	6.32 (2.15-18.64)	.001
Vocational, Technical, Business, or Trade Certificate or Diploma	8.67 (2.18-34.54)	.002
Some College	7.19 (2.24-23.05)	.001
Associate's Degree	17.08 (3.31-88.15)	.001
Bachelor's, Master's, Professional, or Doctoral Degree	8.26 (2.53-27.03)	<.001
Caregiver Health		.038
Excellent	0.85 (0.29-2.53)	.773
Very Good	1.07 (0.42-2.78)	.884
Good	1.52 (0.60-3.84)	.375
Fair	3.01 (1.12-8.07)	.029
Poor	a	
Caregiver Helps Care Recipient with Personal Care		.015
Every Day	1.99 (0.99-3.98)	.053
	1.64, 0.63-4.26)	.309

Most Days	3.20 (1.52-6.74)	.002
Some Days	2.88 (1.29-6.44)	.010
Rarely	a	
Never		
Care Recipient Argues with Caregiver		.036
A Lot	1.87 (0.75-4.69)	.181
Some	2.83 (1.40-5.72)	.004
A Little	1.81 (0.96-3.41)	.068
Not At All	a	

^a Referent category.

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

Variable	Parameter Estimate (95% Confidence Interval)	p-value
Care Recipient Diabetes	2.10 (1.17-3.77)	.013
Care Recipient Dementia	2.82 (1.40-5.71)	.004
Caregiver Age, Years	0.96 (0.93-0.99)	.022
Caregiver Helps Care Recipient Get Around		.004
Every Day	2.82 (1.20-6.61)	.017
Most Days	5.00 (2.00-12.37)	.001
Some Days	2.90 (1.32-6.37)	.008
Rarely	1.32 (0.51-3.42)	.567
Never	a	
Care Recipient Argues with Caregiver		.006
A Lot	4.84 (1.81-12.93)	.002
Some	2.81 (1.27-6.21)	.011
A Little	1.65 (0.77-3.57)	.200
Not At All	a	
Family Disagrees with Caregiver's Care Choices		.041
Very Much	0.60 (0.13-2.73)	.506
Somewhat	2.83 (1.21-6.63)	.016
Not So Much	a	

^a Referent category.

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

Variable	Parameter Estimate (95% Confidence Interval)	p-value
Care Recipient Heart Disease	1.86 (1.05-3.29)	.034
Care Recipient Lung Disease	1.91 (1.02-3.55)	.042
Care Recipient Dementia	3.13 (1.63-5.98)	.001
Caregiver Health		.000
Excellent Health	0.21 (0.06-0.68)	.009
Very Good	0.32 (0.13-0.81)	.016
Good	0.61 (0.25-1.45)	.260
Fair	1.27 (0.51, 3.15)	.603
Poor	^a	
Caregiver Helps Care Recipient Get Around		.003
Everyday	4.53 (2.07-9.90)	.000
Most Days	3.12 (1.32-7.37)	.010
Some Days	1.92 (0.92-4.04)	.085
Rarely	1.98 (0.88-4.44)	0.97
Never	^a	

^a Referent category.