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Original Article

The caregiver burden of informal caregivers for stroke patients with and without dysphagia: A multi-center, cross-sectional study in Türkiye

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ABSTRACT

Objectives: The aim of this study was to investigate the caregiver burden (CB) of informal caregivers for stroke survivors with and without dysphagia and to assess the relationship between the CB levels of informal caregivers for stroke survivors with dysphagia, patients' swallowing-related quality of life (QoL), and patients' stroke-specific QoL.

Patients and methods: This multi-center, prospective, cross-sectional study included a total of 120 stroke patients (76 males, 44 females; mean age: 61.1±12.3 years; range, 19 to 86 years) between October 2019 and 2020. Of the patients, 57 had dysphagia and 63 had no dysphagia. The Functional Oral Intake Scale (FOIS) was used to classify the degree of functional dietary limitation caused by each patient's swallowing impairment. Patients and caregivers completed the Eating Assessment Tool (EAT-10), Swallowing Quality of Life (SWQoL) questionnaire, Stroke Impact Scale (SIS), and the Zarit Caregiver Burden Interview (ZBI).

Results: The CB levels were higher in those caring for stroke patients with dysphagia than in those caring for stroke patients without dysphagia. Caregiver burden was found to be associated with patients' swallowing-related QoL and stroke-related QoL. Significant predictors of high CB scores (F=2.55, $R2$=0.59; p=0.007) were being an employed caregiver (B=17.48, p=0.003), being a caregiver with high school (B=-19.6, p=0.03), and secondary school (B=-16.28, p=0.02) educational status, being son, daughter (B=30.63, p=0.007) or other relative of the patient (B=20.06, p=0.01), lower FOIS stage (B=-3.14, p=0.011), lower SWQoL (B=0.52, p=0.009) and lower SIS (B=-0.37, p=0.04) scores.

Conclusion: Caregivers of stroke patients with dysphagia suffer from a higher CB than those without dysphagia. In stroke patients with dysphagia, swallowing-related QoL is associated with the QoL levels of stroke patients and the CB levels of their caregivers. Employment status, educational status of caregiver, caregiver's relativity to the patient, FOIS stage, swallowing and stroke related QoL of the patients are factors related to burden levels of caregivers of stroke patients with dysphagia. These results may help health professionals to understand dysphagia as an essential source of CB and consider it, while planning treatments.

Keywords: Caregiver burden, dysphagia, stroke.

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Caregiver burden can be defined as the physical, psychological, emotional, social, and financial stresses that caregivers experience due to the needs of patients during the process of providing care.[1,2] An informal caregiver is an unpaid person (e.g., a relative or a spouse) responsible for caring for an individual with a chronic illness or disability.[2] Becoming an informal caregiver for a person with a disability is a vital life stressor that impairs the caregiver's well-being. Previously, it has been shown that informal caregivers are at risk of experiencing several health problems, such as depression, anxiety, impaired quality of life (QoL), and cardiovascular diseases.[3,4] Experiencing mental or emotional strain related to caregiving is an independent risk factor for caregiver mortality.[5,6] Caregiver burden has also adverse effects on care recipients and caregivers.[4,7-9] A high caregiver burden can cause poorer health outcomes for the caregiver, which may affect the level of care provided to the care recipient and, cyclically; as a result, caregiver burden leads to worse outcomes for care recipient health, as well.[4] It has been demonstrated that caregivers' burden, anxiety, and depression reflect the stroke patients' QoL.[9,10] Caregivers' health is one of the crucial predictors of more prolonged patient survival.[8] Considering the interdependence of patient and caregiver health outcomes, identifying the factors that affect caregiver burden may also help to improve modifiable factors associated with caregiver burden.[1] Current clinical practice guidelines suggest that stroke patients and their families should be included throughout the care process, suggesting collective decision-making regarding goals and treatment planning.[11] Stroke rehabilitation should be carried out with a family-centered approach. The needs of all family members, including patients with stroke, are taken into account throughout all phases of the rehabilitation process. At the same time, the family dynamics are also considered. Identifying factors related to caregiver burden is crucial for implementing a family-centered care approach in stroke rehabilitation. There is a need to have sufficient recognition of contributors to caregiver burden to ease the burden on caregivers. Recognition is required first to establish interventions. Therefore, studies are needed to characterize informal caregivers at risk of increased caregiver burden to maximize health-related and quality-of-life outcomes.[4]

Stroke is the third leading cause of death globally and one of the leading causes of disability. Stroke incidence and prevalence have been reported as 69.6 and 310/per 100,000 in the Turkish population.[12] According to the disability-adjusted life year estimations, cerebrovascular diseases take the third place among 10 conditions that constitute the total disease burden in Türkiye.[13] Stroke causes disability, dependence on others in daily living activities (ADLs), and a need for long-term care, often provided by informal caregivers who lack professional care skills or knowledge.[1] Due to the sudden and unpredictable onset of stroke, stroke survivors and their caregivers often face problems with its impact on daily life. After a stroke, family and family support increases, and providing chronic care for a family member may create a burden.[1,14] Caregiving for a patient with stroke has been associated with higher rates of caregiver burden.[15] Factors affecting caregiver burden in caregivers for patients with stroke have been previously investigated in many systematic reviews and clinical trials. Patients' functional dependency, motor function at stroke onset, the amount of time caregiving,[3] level of dependence in ADLs, neurological function,[1,3,16] cognitive-emotional deficit,[15] caregiver's depression and anxiety,[1,16-18] caregiver's gender, caregiver's employment status[1,19,20] and caregiver stress[17] are predictors of caregiver burden in stroke. Additionally, post-stroke complications such as dysarthria, dysphagia, and aphasia have been shown to affect caregiver burden after stroke.[1,3,19] However, to date, research has focused mainly on stroke characteristics and patients' and partners' demographic characteristics rather than solely focusing on post-stroke complications to explain caregiver burden.[21] For instance, the previous literature has not directly compared caregiver burden levels of patients with and without dysphagia.

Despite improvements in stroke treatment and care, stroke continues to be a devastating disease for patients and their caregivers. After a stroke, patients often suffer from various post-stroke complications.[14] Dysphagia is one of the most common and major complications of stroke. Although many stroke patients recover from swallowing spontaneously, 11 to 50% still suffer from dysphagia at six months.[22] Dysphagia at the time of presentation is an independent predictor of poor outcomes after acute stroke. Dysphagia may lead to several problems, such as dehydration, malnutrition, aspiration pneumonia, and even death.[23] Dysphagia is an important complication of stroke, which causes increased morbidity and mortality. Thus, it is crucial to better understand the relationship between caregiver burden and post-stroke dysphagia. Dysphagia may affect caregiver burden levels in many ways. It may cause a dramatic shift in the typical daily routines of both the patient and the caregiver.[24,25] It may also decrease eating together and social participation.[25,26] Caregivers of patients with dysphagia may abstain from eating together with their care recipients to not upset them.[24] The challenges that dysphagia creates often make mealtime stressful and unpleasant and limit shared mealtimes, negatively impacting caregivers.[24,25,27] Special meal preparation may increase effort.[27] Caregivers of patients with cancer have previously reported increased conscious thought and planned activity in preparing meals.[28] Texture-modified diets also lead to longer mealtime durations.[29] Texture-modified diets have been linked to insufficient nutritional intake.[29] Caregivers may be concerned about whether their relatives are getting enough to eat when they eat specially prepared, texture-modified food. It has been reported that caregivers feel afraid and anxious due to the possibility of care recipients coughing and choking on food.[24,25] The use of feeding tubes has also been associated with a heavy burden.[24] Caregivers of patients using tube feeding also usually feel anxious about the appropriate nutritional status of their patients.[26,28] The scheduled nature of tube feeding and changes in existing eating routines may also be causes of caregiver burden.[25]

The dysphagia-related burden on caregivers of older adults has been investigated in a heterogeneous group of older adults, including patients with Parkinsonism, Alzheimer’s disease (AD), and stroke.[24,25] The inclusion of neurological diseases such as parkinsonism and dementia in addition to stroke may affect caregiver burden independently of dysphagia and limit the generalizability of the results to adult stroke patients of all ages. In their preliminary study, Davis et al.[4] investigated dysphagia-related caregiver burden in spouses of stroke survivors and dyadic-level variables that might contribute to post-stroke caregiver burden. They found that greater care recipient and caregiver perceived impact of dysphagia on mealtime logistics increased diet restrictiveness, and decreased swallowing-related QoL was associated with an increased caregiver burden. However, this previous research had a relatively small sample size and no instrumental assessments of dysphagia severity.

Dysphagia is an important contributor to caregiver burden, while the dysphagia-specific burden in stroke has not been investigated sufficiently in the previous literature. Also, no study has been found in the literature comparing the caregiver burden levels of the informal caregivers of stroke patients with and without dysphagia. Considering the fact that the interdependence between the care recipient and the caregiver should be considered to optimize the health of both, there is a need for studies to further enlighten the caregiver burden related to dysphagia in stroke. A very recent up-to-date systematic review on the burden in caregivers of adults with dysphagia concluded that further research is required to better explore the burden, particularly in those specific to the various etiologies of dysphagia, to better meet the needs of our patients.[30] In the present study, we hypothesized that higher caregiver burden levels would be associated with reduced patients' swallowing-related QoL and stroke-specific QoL. We, therefore, aimed to compare the caregiver burden of informal caregivers for stroke survivors with and without dysphagia. Our secondary objective was to assess the relationship between the caregiver burden levels of informal caregivers for stroke survivors with dysphagia, patients’ swallowing-related QoL, and patients’ stroke-specific QoL and to identify factors predicting caregiver burden in stroke patients with dysphagia. Our third objective was to compare caregiver burden levels of caregivers of stroke patients with aspiration to those with penetration and patients who were tube-dependent to those who were not tube-dependent. Also, we aimed to reflect the Turkish perspective on dysphagia-related caregiver burden, given that most previous research is coming out of North America.

PATIENTS AND METHODS

Study design and setting

This multi-center, prospective, cross-sectional study was conducted by the members of the Dysphagia Rehabilitation Research Group of the Turkish Society of Physical Medicine and Rehabilitation (TSPMR), who provide stroke and dysphagia rehabilitation in 10 different university or education and research hospitals in Türkiye between October 2019 and 2020.

In line with our national practice guidelines, all the patients underwent detailed examination and Eating Assessment Tool (EAT-10) as a first-line screening test for dysphagia. Afterward, patients were assessed via one of the instrumental methods (fiberoptic endoscopic evaluation of swallowing [FEES] or Videofluoroscopic Swallow Study [VFSS]) in the second-line evaluation methods.[31] Patients with documented dysphagia by FEES and VFSS were defined as patients with dysphagia and those without instrumentally detected dysphagia were defined as patients without dysphagia.

Inclusion criteria were as follows: age ≥18 years; unilateral stroke; Functional oral intake scale (FOIS) 1,2,3,4,5,6,7; Modified Rankin Scale (mRS) 3,4; Brunnstrom upper extremity scale 2,3,4; being ambulatory with or without an assistive device; Functional Ambulation Classification (FAC) 2,3,4; stroke patients with dysphagia symptoms after two months post-stroke (for patients with dysphagia); and patients whose caregivers agreed to participate in the study. Patients with similar degrees of motor impairment were included to avoid interference between these variables and outcomes. Patients with another concomitant neurological disease, swallowing impairment before stroke, severe mental impairment, severe incontinence, or severe speech disorders were excluded to minimize the influence of factors other than dysphagia on caregiver burden. Informal caregivers were individuals older than 18 years who lived with the patient and had the major responsibility for the patient's care. Formal caregivers were excluded. Finally, among 129 patients with stroke assessed, nine were excluded, and 120 (76 males, 44 females; mean age: 61.1±12.3 years; range, 19 to 86 years) were enrolled. The study flowchart is shown in Figure 1.

Protocol and measures

Patient characteristics, such as age, sex, type of stroke, stroke lesion, Brunnstrom stage,[32] mRS,[33] and FAC,[34] and caregiver characteristics, such as employment status, educational status, caregiver's relation to the patient, and caregiving time, feeding tube-dependency status were recorded. The EAT-10 was used to screen for self-perceived oropharyngeal dysphagia symptom severity and risk of oropharyngeal dysphagia.[35] The presence of dysphagia was documented either with FEES or VFSS by using the Penetration Aspiration Scale (PAS).[36,37] In addition, FOIS and The Dysphagia Outcome and Severity Scale (DOSS) levels of patients were recorded.[38,39] To assess the stroke-related QoL, the Stroke Impact

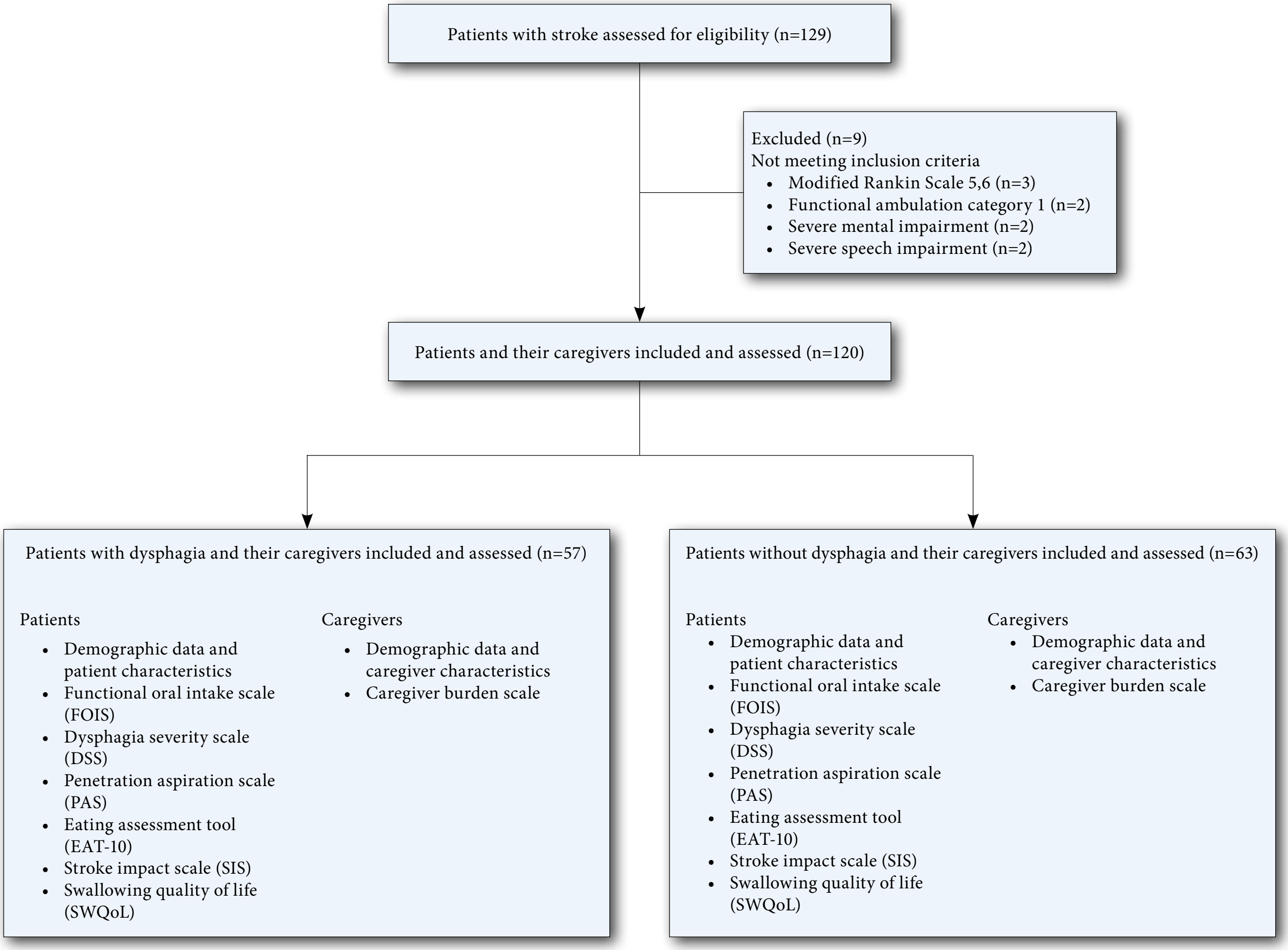

Figure 1. Study flowchart.

Scale (SIS) was used.[20,40] The Swallowing Quality of Life (SWQoL) questionnaire was used to evaluate the swallowing-related QoL.[41] Participants completed the questionnaires by themselves or with the help of their caregivers. The Zarit Caregiver Burden Interview (ZBI) was completed by caregivers to evaluate caregiver burden levels.[42]

Brunnstrom recovery stage

The motor recovery of patients was assessed clinically with Brunnstrom recovery stage which is often used as a valid test for classification of stroke patients in terms of post-stroke motor recovery sequences based on the degree of spasticity and selective voluntary movement.[32,43]

Modified Rankin scale

The mRS is a frequently applied tool to record stroke patients' degree of overall independence.[33] It is a valid, reliable and commonly used tool to assess the impact of new stroke treatments. It consists of items, ranging from 0 to 6 which corresponds to perfect health without symptoms (0) to death (6).[44]

Functional Ambulation Category

The FAC is a frequently used, valid, simple-to-use, and easy-to-interpret, six-point tool which is used for grading clinical walking ability.[34] Walking ability is classified from ‘’inability to walk’’ (Category 0) to “independent walking” (Category 6) by determining how much support is needed during walking, regardless of whether or not they use an assistive device.

Eating assessment tool

The EAT-10 was developed and validated to predict oropharyngeal dysphagia severity and changes after treatment.[35] It consists of 10 questions about the severity of the symptoms of oropharyngeal dysphagia. Each question is scored from 0 to 4 (“no problem” to “severe problem”). The total score is calculated by summing each question's score.[35,45] A total score of ≥3 is considered consistent with the risk of oropharyngeal dysphagia.[46] The scale has been validated in Turkish by Demir et al.[47]

Penetration aspiration scale

The PAS is an eight-point scale is utilized to describe the depth and response to airway infiltration during videofluoroscopy and FEES.[36,37,48] Depth of airway invasion, the material remaining after swallowing, and a patient's response to aspiration are evaluated by the scale.[49] One point corresponds to no penetration or aspiration, 2 to 5 points penetration, and 6 to 8 points aspiration.[50]

Functional oral intake scale

The FOIS was developed to document changes in patients’ functional eating abilities.[51] Swallowing abilities were assessed with the FOIS, including seven categories describing the quality of oral intake, ranging from 1 (worst) to 7 (normal) as follows:

Level 1: Nothing by mouth.

Level 2: Tube-dependent with minimal attempts of food or liquid.

Level 3: Tube-dependent with consistent oral intake of food or liquid.

Level 4: Total oral diet of a single consistency.

Level 5: Total oral diet with multiple consistencies but requiring special preparation or compensations.

Level 6: Total oral diet with multiple consistencies without special preparation but with specific food limitations.

Level 7: Total oral diet with no restrictions.

A score of 5 or lower is compatible with dysphagia, and patients require dietary adjustments for normal function.

The dysphagia outcome and severity scale

The DOSS is a seven-point comprehensive ordinal scale that was developed to systematically rate the functional severity of dysphagia and make recommendations for diet level, independence level, and type of nutrition based on videofluoroscopic findings; however, several studies also validated the DOSS reliability for FEES.[38,39] It is used to summarize the functional problem.[52] Patients are classified into different swallowing classes, from Stage 7, considered normal alimentation, to Stage 1, which defines patients with severe dysphagia and no possible oral food intake.[39,52]

Stroke impact scale

The SIS 3.0 is a 59-item self-report assessment of stroke outcomes used to evaluate health-related QoL.[40] It has eight domains: strength, hand function, mobility, physical and instrumental ADLs (or IADLs), memory and thinking, communication, emotion, and social participation. Scores for each domain range from 0 to 100, with higher scores indicating a higher QoL. The strength items are rated in terms of the amount of strength; memory, communication, ADLs/IADLs, mobility, and hand function items are rated in terms of the amount of difficulty; and emotion and social participation items are rated in terms of frequency. Composite physical domain is obtained by combining four subscales (strength, hand function, ADLs/IADLs, and mobility). The SIS 3.0 also contains a question (item 50) that evaluates the patient's perception of healing. The patient is asked to rate his/her perception of recovery on a Visual Analog Scale (VAS) of 0 to 100, with 0 meaning no recovery and 100 meaning full recovery.[53] The validity and reliability of this test in Turkish have been shown by Özmaden Hantal et al.[54]

Swallowing quality of life questionnaire

The SWQoL consists of 44 items. It includes 10 subscales: burden, eating duration, eating desire, food selection, communication, fear, mental health and social functioning, fatigue, and sleep.[41] All subscales range from 0 to 100, and a higher score indicates less impairment.[55] The questionnaire has been translated into Turkish by Demir et al.[56]

Zarit caregiver burden scale

Caregiver burden is measured by the ZBI, developed by Zarit et al.[42] It is the most commonly referenced scale in studies investigating caregiver burden. It is comprised of 22 items. The 22 items reflect the respondent's areas of concern: health, social, and personal life, financial situation, emotional well-being, and interpersonal relations. Each item is scored from 0 to 4, where 0= never, 1= rarely, 2= sometimes, 3= quite frequently, and 4= nearly always. Caregiver burden is evaluated by means of the total score obtained from adding up the scores of each item, which can vary from 0 to 88. Higher scores indicate a higher burden.[57] The scale has been validated in Turkish by Inci and Erdem,[58] and its psychometric characteristics have been studied in family caregivers of inpatients in medical and surgical clinics by Ozer et al.[59]

Statistical analysis

The required sample size was calculated using Open Epi Software (https://www.openepi.com/SampleSize/SSCohort.htm). If the proportions of dysphagia prevalence for patients with and without stroke were 23%[60] and 3%[61] and the ratio of unexposed to exposed was 1, 120 patients would be required to obtain statistically significant results with an alpha error of 0.05 and power of 0.9.

Statistical analysis was performed using the SPSS for Windows version 20.0 software (IBM Corp., Armonk, NY, USA). Continuous data were presented in mean ± standard deviation (SD) or median (min-max or 25th-75th percentiles), while categorical data were presented in number and frequency. The histogram and normality plots and the Kolmogorov-Smirnov or Shapiro-Wilk normality tests were used to evaluate the distribution of data depending on the sample size of groups compared. Descriptive analyses were performed to examine the demographic data. Characteristics of patients and their caregivers and demographic data were compared using independent samples t-test for continuous variables and chi-square test for qualitative variables. The Mann-Whitney U test or independent samples t-tests were used to compare patients with and without dysphagia, patients with aspiration and penetration, and patients who were tube-dependent and were not tube-dependent. The associations between caregiver burden levels and FOIS stage, DOSS stage, EAT-10 total score, SWQoL, and SIS were analyzed in patients with dysphagia using the Pearson correlation analysis. A multiple linear regression analysis (enter method) was also carried out using the ZBI as the dependent variable to predict the association between caregiver burden, patient and caregiver related variables and dysphagia-related outcome measurements in patients with dysphagia. In this analysis, we included significant factors ($p<0.05$) from the univariate analysis, as well as patient and caregiver-related variables and dysphagia-related outcome measurements, since these factors could influence the results. For multiple linear regression analysis, quantitative variables were treated as continuous variables. Other variables including sex, caregiver's employment status, caregivers' educational status and caregiver's relativity to the patient were treated as categorical variables and were modelled using dummy variables. A p value of <0.05 was considered statistically significant.

RESULTS

The number of patients with and without dysphagia included from centers following the affiliation order under the article title above were as follows: Center 1 (n=6); Center 2 (n=2), Center 3 (n=33), Center 4 (n=23), Center 5 (n=12), Center 6 (n=10), Center 7 (n=10), Center 8 (n=13), Center 9 (n=10), Center 10 (n=1). Patients' and caregivers' characteristics are shown in Table 1. Fifty-seven patients with dysphagia and 63 patients without dysphagia were recruited for the study. The mean time since stroke was 15.4±12.5 months in patients without dysphagia and 10.6±10.1 months in patients

TABLE 1
Patients and caregivers' characteristics

	Patients without dysphagia (n=63)					Patients with dysphagia (n=57)					
Characteristics	n	%	Mean±SD	Median	Min-Max	n	%	Mean±SD	Median	Min-Max	*p**
Age (year)			61.7±10.3		59.1-64.3			60.4±14.3		19-86	0.573
Sex											0.317
Female	23	36.5				21	36.5				
Male	40	63.5				36	63.2				
Time since stroke (month)			15.4±12.5					10.6±10.1			0.012
Stroke type											0.053
Ischemic	56	88.9				43	75.4				
Hemorrhagic	7	11.1				14	24.6				
Stroke side											0.388
Right	37	58.7				29	50.9				
Left	26	41.3				28	49.1				
Dominant side											0.465
Right	52	82.5				44	77.2				
Left	11	17.5				13	22.8				
Stroke lesion											0.001
Supratentorial	58	92.1				38	66.7				
Infratentorial	5	7.9				19	33.3				
Brunnstrom stage upper extremity proximal				4	2-4				3	2-4	0.594
Brunnstrom stage upper extremity distal				4	1-5				3	1-6	0.152
Brunnstrom stage lower extremity				4	2-6				4	2-6	0.719
Modified rankin score				3	3-4				3	3-4	0.091
Functional ambulation category				3	2-4				3	2-4	0.085
Functional oral intake scale				7	5-7				5	1-6	0.0001
Dysphagia outcome and severity scale				7	5-7				3	1-6	0.0001
Caregivers' age (year)			44.4±13.5					45.8±15			0.636
Caregivers' sex											0.934
Female	46	73				42	73.7				
Male	17	27				15	26.3				
Caregivers' employment status											0.618
Employed	16	25.4				14	24.6				
Unemployed	47	74.6				43	75.4				
Caregivers' educational status											0.761
Illiterate	9	14.3				9	15.8				
Primary school	21	33.3				21	36.8				
Secondary school	17	27				10	17.5				
High school	13	20.6				15	26.3				
University	3	4.8				2	3.5				
Caregiver's relativity to the patient											0.249
Husband/wife	28	44.4				28	49.1				
Son	14	22.2				10	17.5				
Daughter	12	19				5	8.8				
Sister/brother	2	3.2				1	1.8				
Other	7	11.1				13	22.8				
Caregiver's caregiving time											0.376
<4 h/day	12	19				13	22.8				
5-8 h/day	8	12.7				8	14				
9-12 h/day	3	4.8				7	12.3				
>12 h/day	40	63.5				29	50.9				

SD: Standard deviation; * P value by independent samples t-test or chi-square test.

with dysphagia. The groups were similar in terms of age (p=0.873). The time elapsed since the stroke in patients with dysphagia was statistically significantly lower than those without (p=0.012) (Table 1). The median Brunnstrom stage score of the proximal upper extremity was four in patients without dysphagia and three in patients with dysphagia. The median FAC of patients with and without dysphagia was 3. A total of 74.6% of the caregivers of patients without dysphagia and 75.4% of the caregivers of patients with dysphagia were unemployed. Most of the caregivers were husbands or wives of the patients. Most of the caregivers were responsible for the care of the patients for over 12 h a day. The ZBI scores were statistically significantly higher in patients with dysphagia than those without dysphagia.

The SIS total scores were significantly higher in patients without dysphagia than in patients with dysphagia (p=0.003). Scores of mobility, ADL, memory, communication, emotion subdimensions and the composite physical score of the SIS were statistically significantly lower in patients with dysphagia (p=0.002, p=0.037, p=0.0001, p=0.0001, p=0.033; consecutively) (Table 2). The SWQoL total score and its subscales-general burden, eating duration, eating desire, symptoms, food selection, communication, fear of eating, social functioning, mental health, sleep, and fatigue were significantly lower in patients with dysphagia (p<0.001) (Table 2). In patients with dysphagia, the ZBI scores were negatively correlated with the SWQoL total score (r=-0.329, p=0.004) and its subscales: general burden, food selection, social functioning, and sleep (Table 3). The ZBI scores were also negatively correlated with SIS total scores (r=-0.273, p=0.041) (Table 3). A multiple linear regression analysis was performed to determine the relative contributions of patient and caregiver factors in evaluating caregiver burden in patients with dysphagia. The multiple linear regression model showed significant predictors of high caregiver burden scores (F=2.55, *R2*=0.59; p=0.007) were being an employed caregiver (B=17.48, p=0.003), being a

TABLE 2
Comparison of patients with and without dysphagia

Outcome measurements	Patients without dysphagia (n=63)		Patients with dysphagia (n=57)		
	Median	25th-75th percentile	Median	25th-75th percentile	*p**
The Zarit Caregiver Burden Scale	38	29-43	42	36-53	0.003
Stroke Impact Scale	53.33	45.29-60.29	45.16	39.75-52.32	**<0.001**
Strength	60	50-75	55	40-65	0.096
Hand function	32	20-52	28	20-50	0.491
Mobility	53.33	51.11-71.11	48.88	36.66-60	**0.002**
Daily living activities	23	19-29	21	17-26	**0.037**
Memory	74.28	54.28-82.85	60	42.85-74.28	**<0.001**
Communication	80	71.42-88.57	60	48.57-74.28	**<0.001**
Emotion	60	57.77-68.88	60	55.55-66.66	**0.033**
Social participation	42.5	20-60	37.5	20-46.25	0.191
Patient's global assessment of recovery	50	30-70	40	20-50	0.094
Composite physical	43.91	36.94-52.5	39	31.29-48.34	**0.033**
SWQoL total score	91.47	85.27-100	59.32	50.86-68.13	**<0.001**
General burden	100	100-100	60	60-80	**<0.001**
Eating duration	100	100-100	70	60-80	**<0.001**
Eating desire	100	93.33-100	73.33	60-86.66	**<0.001**
Symptoms	98.57	87.14-100	64.28	54.29-77.14	**<0.001**
Food selection	100	80-100	60	40-80	**<0.001**
Communication	100	80-100	60	40-80	**<0.001**
Fear of eating	100	100-100	60	42.5-75	**<0.001**
Social functioning	100	84-100	40	40-66	**<0.001**
Mental health	100	100-100	52	40-68	**<0.001**
Sleep	90	70-100	60	40-60	**<0.001**
Fatigue	80	60-100	46.66	40-60	**<0.001**
EAT-10	0	0-2	20	13-24.5	<0.001

SWQoL: Swallowing Quality of Life questionnaire; EAT-10: Eating assessment tool-10; * p value by Mann-Whitney U test

TABLE 3
Correlation between The Zarit Caregiver Burden Scale and FOIS stage, DOSS stage, EAT-10 total score, SWQoL and Stroke Impact Scale

Outcome measurements	The Zarit Caregiver Burden Scale	
	CI	*p*
FOIS stage	-0.2	0.062
DOSS	-0.137	0.311
EAT-10 total score	0.211	0.121
SWQoL total score	-0.329*	0.012
General burden	-.0278*	0.036
Eating duration	-0.143	0.287
Eating desire	-0.213	0.112
Symptoms	-0.225	0.093
Food selection	-0.347**	0.008
Communication	-0.104	0.441
Fear of eating	-0.196	0.144
Social functioning	-0.314*	0.017
Mental health	-0.239	0.073
Sleep	-0.388**	0.003
Fatigue	-0.214	0.111
Stroke Impact Scale	-0.273*	0.040
Strength	-0.13	0.337
Memory	-0.305*	0.021
Mobility	-0.314*	0.017
Social participation	-0.016	0.906
Emotion	-0.208	0.121
Communication	-0.087	0.521
Daily living activities	-0.327*	0.013
Hand function	-0.102	0.450
Patient’s global assessment of recovery	-0.187	0.163
Composite physical	-0.236	0.078

FOIS: Functional Oral Intake Scale; DOSS: The Dysphagia Outcome and Severity Scale; EAT-10: Eating Assessment Tool-10; SWQoL: Swallowing Quality of Life questionnaire.

caregiver with high school (B=-19.6, p=0.028), and secondary school (B=-16.28, p=0.028) educational status, being son, daughter (B=30.63, p=0.007) or other relative of the patient (B=20.06, p=0.011), lower FOIS stage (B=-3.14, p=0.011), lower SWQoL (B=0.52, p=0.009) and lower SIS (B=-0.37, p=0.035) scores (Table 4).

In patients with dysphagia, median scores of PAS for 3 mL, 5 mL, 10 mL, and 20 mL water, one dessert spoon of yogurt and cracker were 2 (range, 1 to 8), 3 (range, 1 to 8), 3 (range, 1 to 8), 3 (range, 1 to 8), 3 (range, 1 to 8) and 4 (range, 1 to 8), respectively.

When patients with aspiration and penetration (water, yogurt, and solid food) were compared, no statistically significant differences were detected between them in terms of the ZBI scores (Table 5). There was a statistically significant difference in terms of SWQoL total score and EAT-10 scores between patients who were tube-dependent and patients who were not tube-dependent based on FOIS (p=0.03 and p=0.0001, respectively). However, no statistically significant difference was detected in terms of the ZBI scores (Table 5) or SIS total scores between patients who were tube-dependent and patients who were not tube-dependent based on FOIS (p=0.353, p=0.233, respectively).

DISCUSSION

In the present study, we evaluated dysphagia-specific burden in patients with stroke, compared caregiver burden levels of caregivers tending to patients with dysphagia and patients without dysphagia, and assessed the relationship between caregiver burden, patients’ swallowing-related QoL, and stroke-specific QoL. Caregivers of patients with dysphagia reported higher caregiver burden levels than caregivers of patients without dysphagia. In patients with dysphagia, higher caregiver burden levels were associated with lower swallowing-related QoL and lower stroke-specific QoL. Being employed compared to unemployed, having a high and secondary school educational status compared to university, and being a son, daughter, or another relative of the patient compared to being spousal were found to be caregiver-related factors associated with caregiver burden. Lower FOIS stage, lower SWQoL, and SIS scores were also determined as other predictors of caregiver burden levels. Caregiver burden levels were similar among caregivers of patients with aspiration and penetration and caregivers of tube-dependent patients and tube non-dependent patients.

Several previous systematic reviews regarding factors related to caregiver burden in stroke have not demonstrated a specific relationship between dysphagia and caregiver burden.[1,14,17,62] Therefore, the current study adds to the growing literature base not only about the caregiver burden in patients with stroke, but also about dysphagia-specific caregiver burden. The results indicate that, compared to caregivers of stroke patients without dysphagia, caregivers of stroke patients with dysphagia are more likely to

TABLE 4
Multiple regression analysis explaining caregiver burden and dysphagia

Parameters	Unstandardized coefficient (B)	Standardized coefficients (β)	Lower 95% CI	Upper 95% CI	*p*
Constant	76.80		9.12	144.49	0.027
Patient's age	-0.04	-0.05	-0.41	0.32	0.809
Sex					
Male	-4.78	-0.18	-13.67	4.103	0.282
Female					
Caregiver's age	0.41	0.45	-0.08	0.89	0.099
Caregiver's sex					
Male	7.81	0.26	-2.86	18.47	0.146
Female					
Caregiver's employment status					
Employed	17.48	0.56	6.36	28.59	**0.003**
Unemployed					
Caregiver's caregiving time					
5-8 h/day	-5.20	-0.14	-18.51	8.11	0.433
9-12 h/day	-9.12	-1.30	-23.31	5.08	0.201
>12 h/day	2.74	0.10	-8.22	13.69	0.615
<4 h/day					
Caregivers' educational status					
University	-8.48	-0.31	-1.71	6.2	0.251
High school	-19.59	-0.64	-36.99	-2.19	**0.028**
Secondary school	-16.28	-0.44	-30.24	-2.32	**0.028**
Illiterates					
Caregiver's relativity to the patient					
Son, daughter	30.63	0.08	8.94	52.31	**0.007**
Sister/brother	-1.02	-0.01	-29.94	27.905	0.944
Other	20.06	0.63	4.98	35.14	**0.011**
Husband/wife					
Functional oral intake scale stage	-3.14	-0.42	4.98	35.14	**0.011**
Dysphagia outcome and severity scale	1.47	0.14	-1.7	4.64	0.353
Eating assessment tool-10	-0.42	-0.27	-1.32	0.48	0.352
Swallowing quality of life questionnaire	-0.52	-0.57	-0.9	-0.014	**0.009**
Stroke impact scale	-0.37	-0.32	-0.71	-0.03	**0.035**

CI: Confidence interval.

suffer from caregiver burden. In addition, caregiver burden is associated with swallowing-related QoL and stroke-related QoL. These findings also add to the rising literature on the dysphagia-related caregiver burden. Byeon[63] investigated the levels of caregiver burden and knowledge of dysphagia management in a survey research study conducted with caregivers of hospitalized stroke patients. However, in this study, caregiver burden in patients with all types of nutritional status, including patients with oral intake, nasogastric, or gastrostomy tube, was measured, and caregiver burden levels of patients with and without dysphagia were not compared. Choi-Kwon et al.[19] also investigated the factors associated with caregiver burden in patients with stroke in Seoul, Korea. They found that unemployment, diabetes mellitus, aphasia, dysarthria, dysphagia, cognitive dysfunction, high mRS, and depression were related to caregiver burden.

Previously, the impact of dysphagia on the caregiver burden of caregivers of the elderly has been investigated.[24,25,27] Shune et al.[25] reported

TABLE 5
Comparison of caregiver burden scores of patients with penetration and aspiration and patients who are tube-dependent and patient who are not tube-dependent

		The Zarit Caregiver Burden Scale score		
Patients	n	Median	25th-75th percentile	*p**
Patients with water penetration	38	40.5	35.5-53.25	0.431
Patients with water aspiration	17	47	36-52.5	
Patients with yogurt penetration	39	41	36-53	0.085
Patients with yogurt aspiration	14	41	36-53	
Patients with solid food penetration	35	40	34-53	0.091
Patients with solid food aspiration	17	50	41.5-58	
Patients who are tube-dependent	15	48.07	14.24	0.233
Patients who are not tube-dependent	43	43.09	13.31	

* P value by Mann-Whitney U test or independent samples t-test.

that spousal caregivers of community-dwelling elderly individuals with dysphagia experienced a more significant emotional burden than caregivers of spouses of older adults without dysphagia, and 70% of caregivers of the elderly rated the level of the burden they suffer as moderate to severe. Similarly, Namasivayam-MacDonald and Shune[27] reported that self-reported swallowing difficulties were associated with an increased emotional and physical burden, when other known factors that impact caregiver burden were controlled.

In line with the results of the current study, Rivière et al.[64] showed that the caregiver burden of caregivers for patients with AD whose feeding behaviors changed was higher than the burden of caregivers for patients with AD whose feeding behaviors did not change. A systematic review examined the literature regarding caregiver burden in caregivers of the elderly with dysphagia-studies in which adults over sixty were included.[24] Unfortunately, the review was able to identify only four studies with participants whose diagnoses were advanced dementia, advanced Parkinson's disease, AD, and chronic ischemic stroke.[19,64-66] However, none of these studies primarily focused on the dysphagia-related burden. Nor did they measure dysphagia with FEES and VFSS, the gold-standard methods for studying the oral and pharyngeal mechanisms of swallowing difficulties and for evaluating the efficacy and safety of swallowing. The methods for attributing dysphagia to patients were self-report, use of feeding tubes, and the subsection of the Aversive Feeding Behaviour Inventory. In the present study, dysphagia was documented by either FEES or VFSS, and only patients with stroke were included.

An updated systematic review has been conducted by Rangira et al.[30] to examine the burden of caregivers of adults with dysphagia regardless of etiology. This time they included adults of all ages, unlike the previous review by Namasivayam-MacDonald and Shune,[24] which only included older adults. Similar to the results of the previous review by Namasivayam-MacDonald and Shune,[24] the methods for measures of swallowing varied across studies and no studies measuring dysphagia using instrumental swallowing assessment methods were identified. This recent meta-analysis revealed that 71% of caregivers of adults with dysphagia experience some degree of burden, while 16% of caregivers suffered from heavy burden associated with caring for someone with dysphagia. Based on the current systematic review results, among the caregivers of patients with stroke, factors related to burden were anxiety levels of the caregiver, physical deficits of the patient, social isolation, and decisions about placement of feeding tubes. The causes of dysphagia-related burden in all medical diagnoses were changes in meal preparation, deterioration in lifestyle, effects on social life, lack of support, decisions regarding placement of feeding tubes, and fear of aspiration. Similarly, the present study results demonstrated that caregiver burden scores were associated with food selection and social functioning subscales of SWQoL.

Differences may occur in PAS obtained from FEES and videofluoroscopy. A higher degree of penetration or aspiration in videofluoroscopy can be seen, as intra-deglutitive events may be missed in swallowing endoscopic assessment or false-positive events due to lack of lateral dimension. Higher penetration or aspiration scores may be observed during swallowing endoscopy owing to better visualization of the anatomical structures such as the vocal cords.[50] Since there may be differences in PAS obtained from FEES and videofluoroscopy, it may be thought that using two different instrumental assessment tools for dysphagia and evaluating these groups together may be contradictory. However, a highly strong correlation between PAS obtained from videofluoroscopy and swallowing endoscopy during simultaneous swallowing endoscopy and videofluoroscopy has been verified. The two techniques have shown to be equally effective in discriminating between penetration and aspiration, and FEES was as reliable as VFSS while using the PAS.[36] Therefore, both instrumental assessment tools for dysphagia can be viewed as diagnostic gold standards for oropharyngeal dysphagia.[36,48]

Oni et al.[67] reported that caregiver burden was associated with incontinence and more severe poststroke disability. In addition, to decrease the contribution of other factors that may influence caregiver burden, patients with severe post-stroke complications, such as severe mental impairment, severe incontinence, and mild or extreme degrees of motor involvement, were excluded from the present study. Depending on the current study results, stroke-specific QoL measured via the SIS was lower in patients with dysphagia than in patients without dysphagia. Although we attempted to decrease the influence of factors other than dysphagia, patients with dysphagia demonstrated a lower stroke-specific QoL related to mobility, ADLs, memory, communication, emotion, and lower physical function. These results prove the difficulty of demonstrating dysphagia-specific caregiver burden in quantitative studies. In addition to quantitative studies, qualitative studies are urgently needed to better understand and demonstrate the caregiver burden specific to dysphagia.

The current study results showed an association between swallowing-related QoL, stroke-specific QoL, and caregiver burden levels. Similarly, Leow et al.[68] reported that swallowing-related QoL was associated with QoL in patients with Parkinson’s disease who experienced dysphagia. In line with the present study results, Shune et al.[69] found that caregiver burden levels were associated with perceived swallowing impairment.

Contrary to previous studies, in the present study, caregiver burden levels were similar among patients with aspiration and patients with penetration and among patients who were tube-dependent and not tube-dependent.[65,70] Unlike the existing literature, Ertem and Ilik[70] demonstrated that caregivers of stroke patients reported a lower caregiver burden with percutaneous endoscopic gastrostomy feeding than oral feeding. Although caregiver burden was high in stroke patients with dysphagia compared to those without dysphagia, this was an unexpected result. Caregivers report fear of aspiration and adequate nutrition as contributing factors to caregiver burden.[24,30] The gastrostomy feeding tube can reduce malnutrition and sequelae and improve survival in patients with inadequate oral intake without causing fear of aspiration in caregivers.[70] Similar levels of caregiver burden in patients with dysphagia and without dysphagia may be related to with the use of percutaneous endoscopic gastrostomy feeding consideration of the patient was adequately fed compared to oral feeding, and this might have caused a decrease in workload and decrease in caregiver's anxiety and burden. Sociocultural differences can also explain this situation. The Turkish culture has the ultimate respect for the elderly and considers care for the sick and elderly sacred; thus, complaining about patient care is not acceptable. Sociocultural effects on caregiver burden in stroke were previously observed in a study conducted by Choi-Kwon et al.[19] The authors found that being a female caregiver was associated with high levels of caregiver burden. This was explained by the sociocultural properties of Korea, namely the fact that caregivers are usually female family members who do not work and are taking care of the whole household. In their study investigating the burden of Chinese family caregivers for stroke patients, Tang et al.[61] reported that factors related to caregiver burden might differ depending on cultural differences. In line with the present study results, Ertem and Ilik[70] reported that carers of patients who were fed orally and patients on percutaneous endoscopic gastrostomy both showed moderate levels of caregiver burden. Given our dependence on informal caregivers for the care of stroke patients in Türkiye, the results of these studies are worthy. Unlike in Western countries, patients are usually cared for by their informal caregivers at their houses, since nursing homes and institutes for patients are not common. The results suggest that caregivers feel a strong responsibility for caring for their relatives. Contrary to what might be expected, they reported similar levels of caregiver burden from oral and tube feeding. Further qualitative studies may yield a more insightful assessment of the dysphagia-related burden with the employment of focus group interviews. This study is also the first to demonstrate dysphagia-specific burden outside North America, reflecting the Turkish perspective on dysphagia-related caregiver burden. Therefore, it provides valuable information on this subject.

According to the present study results, the caregiver's employment status, educational status, relativity to the patient, lower FOIS stage, lower SWQoL, and SIS scores were the predictors of caregiver burden, whereas the caregiving time was not. Unlike previous studies by Choi-Kwon et al.[19] and Rigby et al.[62] reported caregiving time as a factor related to caregiver burden. Consistent with Tang et al.'s[61] study results, we did not find an association with caregiving time and caregiver burden. In line with the present study results, Tang et al.[61] found that education, and kinship to the patient were associated with caregiver burden in Chinese patients with stroke. In line with the results of the current study, Davis et al.[4] reported decreased swallow-specific QoL measured via SWQoL as a factor associated with dysphagia-related caregiver burden. They also found that severity of oropharyngeal dysphagia, as represented by the degree of diet texture restriction via the International Dysphagia Diet Standardization Initiative Functional Diet Scale (IDDSI-FDS), as a factor related to dysphagia-related caregiver burden. Similarly, in the present study, level of oral intake ability as measured by FOIS stage also was found to be a factor related to caregiver burden. Based on the results of the current study, being employed compared to unemployed, having a high and secondary school educational status compared to university, and being a son, daughter, or another relative of the patient compared to being spousal were caregiver-related factors associated with caregiver burden. In contrast with the results of the present study, Choi-Kwon et al.[19] defined being unemployed and as a caregiver factor related to a high burden in their study investigating factors associated with caregiver burden in stroke survivors in Korea. As aforementioned, it seems that the sociocultural characteristics of that population influence factors related to caregiver burden. Caregivers feel responsibility to take care after their relatives in Türkiye. If the caregiver has to work and look after his/her relative, this may cause increased caregiver burden levels.

Just as the caregiver burden specific to dysphagia has not been investigated in the previous literature, evaluations of caregiver burden are not specific to caregiver burden due to dysphagia. Shune et al.[69] recently published a development and validation study of a dysphagia-related caregiver burden screening tool to identify dysphagia-related caregiver burden. However, further studies should be conducted to investigate the dysphagia-specific caregiver burden with a dysphagia-related caregiver burden screening tool to identify the relationship between dysphagia and caregiver burden.

Nonetheless, there are some limitations to our study. To decrease the contribution of other factors that may influence caregiver burden, patients with severe post-stroke complications, such as severe mental impairment, severe incontinence, and mild or severe motor involvement were not included in the present study. Thus, the study results cannot be generalized to all stroke patients. Additionally, using two different instrumental dysphagia evaluation tools by testing centers instead of one type can also be viewed as a limitation. However, both FEES and videofluoroscopy may equally be a diagnostic gold standard for oropharyngeal dysphagia. The presence of a slight difference in terms of time since stroke between patients with and without dysphagia may be encountered as another limitation. Finally, another limitation that should be considered while interpreting our findings is the number of recruited patients from each center were not equal and this might have caused a clustering effect and selection bias.

On the other hand, being the first study to evaluate caregiver burden related to dysphagia in stroke patients, being a multi-center study, measuring and documenting dysphagia by either FEES or VFSS rather than self-report are the main strengths of the present study. The results of this study would enable health professionals in multidisciplinary stroke rehabilitation teams to recognize dysphagia as an important factor related to caregiver burden to consider it while establishing interventions for rehabilitation programs.

In conclusion, caregivers for stroke patients with dysphagia experience a higher caregiver burden than those without dysphagia. Swallowing-related QoL is associated with QoL and caregiver burden in stroke patients with dysphagia. Stroke rehabilitation outcomes are successful, when family-centered strategies are applied. Health professionals should view stroke patients and family caregivers as a unit within the concept of family-centered care. Identifying contributors to caregiver burden can help health professionals to provide appropriate family-centered care during rehabilitation. Health professionals should be aware of dysphagia as a source of caregiver burden and consider it, while planning interventions for rehabilitation programs. As clinicians working on dysphagia management, we should recognize that the consequences of dysphagia are not limited to the disorder itself and acknowledge the pervasive impact of dysphagia on the entire family system. We should account World Health Organization (WHO) International Classification of Functioning, Disability and Health framework while treating our patients. Given the interdependence of the patient and the caregiver's health, to best meet the needs of our patients with dysphagia, we must also better meet the needs of their caregivers and family. As well as applying interventions for dysphagia-related impairments, we should develop interventions and provide education to decrease the caregiver burden. The current study significantly extends our current knowledge about dysphagia-related caregiver burden in stroke. Further longitudinal studies using dysphagia-specific caregiver burden assessment tools should be conducted to shed light on the caregiver burden associated with dysphagia in stroke.

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