



Psychosocial impacts of dysphagia on informal caregivers of individuals with neurological disorders: a qualitative template analysis

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Abstract

The experiences of caregivers in the management of neurological oropharyngeal dysphagia (OD) and dysphagia's subsequent impact on their quality of life constitute a pivotal yet under-acknowledged facet of person-centred care. This study investigated the impact of dysphagia on the quality of life of caregivers of individuals with different neurological conditions (motor neuron diseases, stroke, Parkinson's disease and parkinsonism). Thirty-one informal caregivers of adults with OD participated in semi-structured interviews (mean age: 67.8 ± 16.4 ; 84% female). Interviews were analysed using a template analysis approach, starting from the "a priori" themes derived from the Caregiver Quality of Life Framework developed by Martin and colleagues (*American Journal of Health Promotion*, 35(7), 1042–1045, 2021). A total of 2305 quotes were categorised into 4 main themes, 24 sub-themes and 71 codes. A high level of intercoder agreement was achieved (Cohen's $\kappa = 0.93$). The results revealed the impacts of OD on caregivers across multiple domains, including physical, social, and psychological, as well as issues related to the environmental context. Despite challenges, positive experiences and personal and social resources were also highlighted. Caregivers also reported feelings of acceptance and resilience, with several noting a strengthened bond with their family member. Isolation can be a challenge, but positive adaptations to shared mealtimes were reported, and support groups were helpful. The primary unresolved needs are related to a lack of support from the Health System. Managing OD is possible because of the vital role of caregivers: they have learned behaviours and strategies to support their care recipients. Family-centred care, specialised teams, psychological support, home assistance and mutual aid groups can boost caregivers' well-being.

Keywords Dysphagia · Caregiver · Qualitative Study · Template analysis

Introduction

Oropharyngeal dysphagia (OD) is a clinical condition that impairs the safety and efficiency of swallowing and may necessitate modified food consistency or alternative feeding methods (Robbins et al., 2002). Notably, dysphagia is a common symptom of neurological disorders (El Halabi et al., 2023), including acute cerebrovascular disease, head trauma, Parkinson's disease (PD) and related disorders,

amyotrophic lateral sclerosis (ALS), and muscular dystrophies (El Halabi et al., 2023). Dysphagia has been shown to harm health status and overall quality of life (Karimi & Brazier, 2016). OD has the potential to result in a number of clinical consequences, including aspiration pneumonia, malnutrition, and dehydration (Mittal et al., 2023). Consequently, it may lead to an increase in the duration of hospitalisation, the risk of morbidity and mortality (Mittal et al., 2023), and the overall cost of treatment. A growing number of studies have also examined its relevant impact on daily activities, including the capacity to participate in social events, dietary habits, and physical well-being (Ekberg et al. 2002; Nund et al. 2014a). The dietary changes resulting from dysphagia can lead to feelings of isolation when eating (Seshadri et al., 2018). This may be because people struggle to find suitable meals (Hellden et al., 2018) or because eating can be uncomfortable due to the food's texture (Shune & Linville, 2019). This can also result in feelings of stigma,

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embarrassment associated with eating in the presence of others and anxiety (Jacobsson et al., 2000). Consequently, the impact of dysphagia and eating modification on Quality of Life (QoL) is detrimental, resulting in adverse emotional states, including anxiety and depression (Jones et al., 2018), embarrassment (Jacobsson et al., 2000), decreased meal satisfaction, increased meal duration, fear of choking and social isolation (Miller et al., 2006).

Although a majority of the extant scientific literature is primarily focused on the needs of the individuals experiencing dysphagia (Ninfa et al., 2021), the negative consequences of dysphagia are also experienced by their family members, particularly as they are often heavily involved in care provision (Robinson et al., 2022, Shune & Namasivayam-MacDonald, 2019). The management of dysphagia has been demonstrated to engender heightened levels of emotional, physical and financial distress among caregivers, which can exert a substantial influence on their overall health and well-being (Rangira et al., 2022; Shune & Namasivayam-MacDonald, 2020). The impact of OD on the relational level is detrimental, resulting in a decline in the enjoyment of meals as a moment of family interaction and limiting participation in social occasions involving shared meals with others (Lisiecka et al. 2020; Nund et al. 2014b; Patterson et al. 2013; Robinson et al. 2022). They encounter difficulties in identifying suitable and safe foods and express concerns about the time-consuming and complex nature of preparing “special” meals (Howells et al. 2021; Nund et al. 2014b). These practical aspects of eating necessitate information from healthcare providers, and shared decision-making between patients, caregivers, and healthcare providers (Johansson & Johansson, 2009). Unfortunately, it may be challenging for health and social care services to provide ongoing, consistent, and timely care (Robinson et al., 2022). At the emotional level, the responsibility for maintaining the care recipients’ nutritional status and reducing the risk of choking can give rise to feelings of fear and anxiety (Howells et al., 2021; Lisiecka et al., 2020). Furthermore, such responsibilities can result in feelings of frustration, sadness and isolation, which can also have a detrimental effect on the quality of life of the care recipient (Robinson et al. 2022; Nund et al. 2014b).

To date, the majority of extant qualitative literature on the impact of dysphagia on caregivers has focused on head and neck cancer (HNC) or on single, often acute, neurological conditions. Specifically, the literature has focused more on stroke conditions (Johansson & Johansson, 2009; Robinson et al., 2022) than on neurodegenerative conditions such as PD (Miller et al., 2006) or ALS (Stavroulakis et al., 2014; Lisiecka et al., 2020). The results of the HNC studies offer interesting insights; however, they are not easily transferable to caregivers of individuals with neurological

impairments (Lisiecka et al., 2020). For the same reason, studies exploring a mixed population of caregivers (e.g., HNC and neurological disorders) may produce heterogeneous results due to differing experiences. It should be noted that caregivers of individuals with HNC commonly assume the exclusive responsibility for a multitude of daily activities, including those related to nutrition and food. In the case of neurodegenerative disorders, the progression of multiple neurological conditions over time engenders an augmentation in the complexity of the care recipient’s requirements and necessitates an escalation in the level of assistance with activities of daily living (including mobility, self-care, personal hygiene, nutrition, and the use of assistive devices). Furthermore, there is often a concomitant escalation in the demands on caregivers concerning medical needs (such as administration of medical care, management of medical appointments, and coordination of therapy) and communication (Coelho & Ferreira, 2012). The impact and significance of dysphagia on caregivers may, therefore, vary depending on the presence of multiple disabilities and symptoms and may be balanced with the presence of general motor problems, weakness and fatigue, and loss of autonomy (Coelho & Ferreira, 2012). As related to the extant literature in the neurological populations, the external validity of findings from disease-specific studies remains uncertain, as does the question of whether family members are similarly affected across all neurological conditions. A significant proportion of the previous studies have also incorporated solely female caregivers and/or spouses (Robinson et al., 2022). However, exploring the experiences of informal caregivers with different roles (son/daughter, husband/wife, parents, brothers/sisters) from a range of cultural and socio-economic backgrounds may facilitate the identification of a more extensive range of experiences and the identification of novel themes with clinical implications. Finally, the majority of qualitative studies on caregivers of dysphagic neurological patients have a relatively small sample size, with fewer than 17 participants (Ninfa et al., 2021). Therefore, there is a necessity to explore the experience of caregiving in neuro populations with mixed aetiology, including both nonprogressive conditions (e.g. stroke) and neurodegenerative conditions.

Further, the extant literature has focused only on the burden associated with caring for individuals with dysphagia (Lisiecka et al., 2020; Rangira et al., 2022). However, in recent years, studies on caregiving have shifted their focus away from the concept of burden because this term is partial and incomplete in capturing the carer’s experience (Yuan et al., 2023). The emphasis on burden also fails to acknowledge the positive aspects of caregiving, which emphasise the gratifications and satisfactions associated with caring, including the feelings of being needed and being with an ill family member (Sales, 2003; Yuan et al., 2023). In light of

the pejorative connotations often attributed to the term “burden”, recent studies have proposed the alternative concept of “quality of life” as a more efficacious means of capturing the experience of the caregiver (Martin et al., 2021; Yuan et al., 2023).

In recent research, Martin and colleagues have proposed the Caregiver Quality of Life Framework (Martin et al., 2021), a modified version of the brief QOL framework developed by the World Health Organization. This framework is predicated on the specific context of assisting a family member or friend with personal needs, domestic chores, and other activities of daily living. The framework identifies four main areas: psychological capacity, psychological state, environment, and social relations. A recent single case study published by Ramkishun and colleagues (2024) on the experience of a caregiver of a dysphagic person highlighted that the caregiving role provided the caregiver with a sense of purpose and belonging, opportunities for personal growth, and empathetic understanding. Relatedly, although caregivers of individuals with head and neck dysphagia have reported multiple negative impacts of caregiving, some did not feel that dysphagia had a negative effect on their relationship (Nund et al., 2014a), while others even pointed to positive aspects (Penner et al., 2012). A number of couples experienced an increase in the amount of time spent in each other’s company, feelings of closeness resulting from facing challenges together as a couple, and the ability to develop a positive attitude (Patterson et al., 2013). Many of these caregivers identified the acceptance of a new normal and the adoption of an attitude of trust as two of their main coping strategies (Nund et al., 2014a; Penner et al., 2012). Clearly, there is a need to better understand the positive aspects of caregiving in the context of dysphagia.

In order to achieve a more comprehensive characterization of the impact of dysphagia on caregivers of people with neurological diseases, it is necessary to conduct a more extensive exploration of the range of caregiving experiences. Such research requires including both acute and neurodegenerative conditions, a focus not only on the burden aspects of caregiving, and larger sample sizes. The present study was thus undertaken to investigate the impact of dysphagia on the quality of life of caregivers of individuals with different neurological conditions, encompassing a range of severities and impairments related to dysphagia.

Methods

Recruitment

A convenience sample of caregivers was recruited through the dissemination of flyers detailing the research study,

which indicated its objectives, inclusion criteria and modalities of participation. The flyers were circulated on several Facebook pages in Italian dedicated to caregivers of individuals with dysphagia (including “Disfagia – Italia”, “Disfa & Mangia”), as well as at several rehabilitation centres frequented by such caregivers. The recruitment process was conducted from November 2023 to March 2024.

Participants

To qualify for participation in the study, respondents were required to meet the following inclusion criteria: (I) age > 18 years old; (II) to be a family caregiver of an adult with a neurological disorder; (III) to be caring for a care recipient experiencing neurological dysphagia (FOIS scale ≤ 5 , Cray et al., 2005) as a result of their disease, as assessed by a speech and language pathologist, and (IV) to have a good knowledge of the Italian language, enabling them to understand the purpose of the research and participate in the interview. Individuals fulfilling the following criteria were excluded from participation in the study: (I) caregivers with a reported medical diagnosis of cognitive or psychological impairment and concomitant use of psychiatric medication, (II) caregivers engaged in the care of disabled children, (III) caregivers caring for individuals without neurological diseases, and (IV) caregivers caring for individuals without dysphagia. No financial compensation was provided to the participants.

A total of 31 participants were recruited, providing sufficient data to achieve thematic saturation and confirm redundancy in the findings (Charmaz, 2006; Morse, 1995). The characteristics of the participant caregivers and care recipients are presented in Table 1. The sample of participants was predominantly female (84%, $n=26$), with a mean age of approximately 67.8 years ($SD=\pm 16.4$). All participants and their care recipients were Italian. Most caregivers were spouses or partners (52%, $n=16$, all heterosexual couples), followed by son/daughter (35.5%, $n=11$). The caregivers’ employment status varied, with 6.5% ($n=2$) having completely relinquished their professional commitments to care for their loved ones. The majority of the sample resided with their care recipients and provided daily care (93.5%, $n=29$), while a small proportion cared for them on an occasional basis (6.5%, $n=2$). The care recipients were predominantly male (64.5%, $n=20$) with a mean age of 59.8 years ($SD=15.3$). All had a condition of neurological aetiology, with conditions divided into two categories: acute events (35.5%, $n=11$) and degenerative diseases (64.5%, $n=20$). The majority of respondents (64.5%, $n=20$) received nutrition exclusively via oral administration (i.e., only per os), with varying degrees of dietary restriction, while the 35.5% of the care recipients ($n=11$) received partial nutrition via

Table 1 Shows aggregated demographic data

Caregivers <i>N</i> =31		<i>N</i>	% or mean±SD
Age (years)		31	67.8±16.4
Gender	<i>Women</i>	26	84%
	<i>Men</i>	5	16%
Relationship with the care recipient	<i>Wife</i>	13	41.9%
	<i>Husband</i>	3	9.7%
	<i>Father</i>	1	3.2%
	<i>Daughter</i>	10	32.3%
	<i>Son</i>	1	3.2%
	<i>Sister</i>	2	6.5%
Work activity	<i>Mother-in-law</i>	1	3.2%
	<i>Full-time worker</i>	12	39%
	<i>Part-time worker</i>	2	6.5%
	<i>Retired</i>	15	48%
Time spent with the care recipient	<i>Resigned from work</i>	2	6.5%
	<i>Daily care</i>	29	93.5%
	<i>Occasional care</i>	2	6.5%
Care Recipients <i>N</i>=31		<i>N</i>	% or mean±SD
Age (years)			59.8±15.3
Gender	<i>Women</i>	11	35.5%
	<i>Men</i>	20	64.5%
Diagnosis	<i>Motor Neuron Diseases</i>	9	29%
	<i>Parkinson Disease and Parkinsonism</i>	11	35.5%
	<i>Stroke and Traumatic Brain Injury</i>	11	35.5%
Level of Diet (FOIS scale)	FOIS 1–3 (tube dependent)	6	16.1%
	FOIS 4 (single texture)	11	35.5%
	FOIS 5 (multiple texture)	15	48.4%
Time from diagnosis (months)		31	83.7±20.7

oral and enteral routes through a feeding tube (i.e., percutaneous endoscopic gastrostomy – PEG) (FOIS 1 - FOIS 3) at the time of the interview, and 13% ($n=4$) were fed via nasogastric enteral nutrition (NET), a method of providing nutritional support by delivering a liquid diet directly into the stomach through a nasally inserted tube, prior to transitioning to full oral nutrition.

Ethics

Ethics approval for the project was granted by the Research Evaluation Committee of the Department of Psychology at the University of Milano-Bicocca.

To protect confidentiality, all interviews were pseudonymised, and the original audio recordings were permanently deleted following transcription. Any personal identifiers or medical history details that could allow participants to be recognized were removed during the transcription process. The anonymised transcripts were securely stored on a password-protected university computer system, with access restricted exclusively to the research team.

Data collection

Semi-structured online interviews were conducted in Italian via video call (Google Meet) by the first author (VC), a female speech therapist with a decade of expertise in neurological rehabilitation. The semi-structured interview grid was developed by the first and last authors (VC, LM) based on a review of the extant literature and the research objectives. The following areas were addressed in each interview: (1) Impact of dysphagia on the carer's and care recipient's lives, (2) Unmet Needs, (3) Resources and Barriers of caregiving, and (4) Dysphagia - Healthcare Services. The complete interview grid is available in the supplementary materials. The interview schedule was designed to be flexible, enabling participants to address topics of their choosing, thereby fostering and sustaining positive rapport. The interviews ranged in duration from 45 to 108 min.

Analysis

The interviews were digitally recorded and orthographically transcribed. A template analysis was conducted in accordance with the procedure established by Brooks and colleagues (2015). The template analysis is not linked to a particular epistemology (Brooks et al., 2015). In this study, a “subtle realist” approach is adopted (Hammersley, 1992). This approach acknowledges that the researchers' perspectives inherently influence research. However, it advocates that phenomena exist independently of the researcher and can be understood through the research process (Brooks et al., 2015). This method involves the application of a coding template constructed using an integrated deductive and inductive procedure. A set of a priori themes and sub-themes is identified and then used to categorise a portion of the data to verify the presence of these themes and sub-themes in the dataset (a deductive procedure). Concurrently, during this analysis, additional codes that were not initially foreseen are identified (an inductive procedure). These new codes are then collated into new themes and sub-themes. This approach enables the construction of the coding template to be guided by the researcher's theoretical perspective while broadening the scope to encompass unanticipated issues by leveraging the participants' unique perspectives.

In the present study, the “a priori” themes were derived from the Caregiver Quality of Life Framework (Martin et al., 2021). The framework was applied to the first subset of data (10 interviews) by two coders to verify its applicability. Through an iterative process, the template was then revised and refined (Brooks et al., 2015). Consequently, “a priori” themes were redefined or removed, and new subthemes were added to capture relevant aspects not currently covered. The resulting coding template was applied to all the

datasets (by VC, a speech therapist and trained in psychology), and this process resulted in some more adjustments that were discussed between the first and last authors until a consensus was reached, which is considered a valuable strategy for minimising coder bias (Edwards et al., 2004).

To assess the clarity and stability of the coding structure, a second trained coder, VG (a psychology Master student), independently applied the finalized codebook to the entire dataset. All coders completed standardized training, which involved discussion of operational definitions and practice coding sessions. The analysis process was supervised by LM (a professor of social psychology with expertise in qualitative methods), who mediated disagreements when needed. Inter-coder reliability was evaluated on the entire dataset. For each coding unit, a coder-by-coder contingency table was generated, and Cohen's kappa (κ) was calculated using the standard formula (O'Connor & Joffe, 2020). The resulting $\kappa=0.93$ indicates excellent inter-coder reliability according to established benchmarks. All discrepancies identified during the reliability check were subsequently reviewed and resolved through discussion, leading to full agreement.

Results

A total of 2305 quotes were codified in 4 main themes, 24 sub-themes and 71 codes. Some potential sub-themes initially derived from the Caregiver Quality of Life Framework were removed by the coding frame because they were not mentioned by the carers interviewed. These included "Freedom and safety", "Physical environment", and "Transport", which are allocated within the theme "Environment" in the Caregiver Quality of Life Framework. Changes were also made to the sub-themes within the "Psychological state" theme; in particular, the sub-theme "negative and positive feelings" was split into two different sections in order to make them more distinct and specific. In addition, the term "feelings" was replaced by "emotions". In addition, an iterative inductive process was employed, commencing with the narrations of the participant caregivers, which resulted in the addition of the sub-themes "Hope", "Self-efficacy", and "Resilience". Concerning "Physical Capacity", we added the term "physical" to the sub-theme "Pain and Discomfort". The final version of the framework can be found in Table 2. The themes are presented with their main sub-themes and codes, as well as illustrative quotes in the following sections.

Physical Capacity

The Physical Capacity theme is comprised of six sub-themes, which explore the impact of carers' management

of dysphagia on their physical and physical well-being (e.g. pain, fatigue, sleep) and their management of daily and work activities (e.g. limitations in mobility and work activity).

All respondents reported narratives regarding the impact of dysphagia on their daily lives, which were subsequently categorised under the subtheme of "Daily activities". The majority of these challenges pertained to the management of mealtimes. A salient challenge pertained to the necessity of modifying dietary habits and culinary practices: "Some things we might avoid, vegetables we might give her instead, as well as minestrone, before she used to eat it in big chunks" (daughter, progressive supranuclear palsy). In addition, a significant proportion of respondents (41%, $n=13$) felt that it was important to choose food that the care recipient liked and to present it in an inviting way, both to encourage motivation to eat and to prevent food refusal: "We had to think of things that she would like, always within the rules. We had to find something appetising every time, so that she could rediscover different flavours... It was important to make her want to eat again, to make her struggle to swallow" (daughter, stroke). The increase in meal preparation time was an inconvenience reported by several caregivers, as more attention was needed to determine the correct consistency and more manual dexterity is required to reach the correct texture: "Obviously, the time is longer, because you cook, you have to make the pasta separately, you have to have the broth ready, you have to blend it, you have to heat it up in the microwave afterwards" (daughter, stroke).

The necessity to consume different consistencies and to have a quiet environment to facilitate safe swallowing led to changes in mealtime behaviour, which in turn appeared to lead to alterations in context (e.g., refraining from watching television, reducing stimuli). These alterations often resulted in losing the ability to perceive mealtimes as a time for social interaction. Furthermore, feelings of guilt arising from the caregivers consuming a more diverse range of foods (as compared to the individuals with dysphagia) could, at times, result in the caregivers adopting behaviours such as social isolation or concealment: "We eat in secret, we say we're going to eat but we do it in shifts, me my son or my daughter" (wife, stroke).

It is therefore not surprising that the majority of carers (52%, $n=16$) reported feeling "tired", "exhausted", and "lacking energy" when caring for their loved one (sub-theme "Energy and fatigue"). Carers reported that fatigue was related to having to deal with identifying appropriate foods for their loved one's diet, taking into account their loved one's tastes, and the need to vary the diet and provide

Table 2 Modified caregiver quality of life framework

Domain	N° of subjects	N° of quotes	Sub-theme	N° of subjects	N° of quotes	Coding			
Physical Capacity			Daily Activities	31	449	New practices in meal preparation (consistency and palatability)			
						Prolonged mealtimes			
						Defining new meal habits			
			Energy and Fatigue	23	71	Fatigue in meal management	7	7	Fatigue and tiredness
									Fatigue in managing dysphagia bureaucracy
									Lack of sleep
									Pain
			Sleep and Rest	3	7	Physical Pain and Discomfort	2	2	Pain
			Psychological State	31	774	Mobility	23	64	Difficulty going out and traveling
Maintaining normalcy in outings and travels									
Work Capacity	8	10				Negative Emotions	31	224	Giving up and reducing work activity
									Frustration
Positive Emotions	11	18				Resilience	9	13	Worry
									Relief
									Enduring and reacting
									Optimism
									Depressive Mood
Hope	5	8				Self-Esteem	14	28	Suffering
			Having gifts						
Self-efficacy	31	157	Memory and Concentration	17	43	Being responsible			
						Sense of effectiveness in managing OD			
						Sense of ineffectiveness in managing OD			
Spirituality, religion, beliefs, values	31	253	Life Satisfaction	12	30	Sense of effectiveness in managing illness			
						Sense of ineffectiveness in managing illness			
						Increased concentration at mealtimes			
						Beliefs about the value of food and eating			
						Beliefs about illness			
Life Satisfaction	12	30	Spirituality, religion, beliefs, values	31	253	Attitudes towards illness: acceptance and denial			
						Balancing quality of life and health prescriptions			
						Balancing OD and other symptoms			
Life Satisfaction	12	30	Spirituality, religion, beliefs, values	31	253	Fatalism			
						Religious beliefs			
Life Satisfaction	12	30	Spirituality, religion, beliefs, values	31	253	Living day by day			
						Reduced life satisfaction			
Life Satisfaction	12	30	Spirituality, religion, beliefs, values	31	253	New balance			

Table 2 (continued)

Domain	N° of subjects	N° of quotes	Sub-theme	N° of subjects	N° of quotes	Coding
Environment	31	639	Recreation	13	34	Lack of time for oneself Preserving time for oneself
			Financial Resources	20	49	Health costs Food costs (food and preparation)
			Home Environment	1	1	Adaptation of the home environment
			Learning and Skill Training	31	162	Training by a professional Self-learning Training others
			Health and social care access and quality	31	393	Lack of information about dysphagia Lack of home care Need for psychological support Inadequate care by carer Helpful support by carer Inadequate health support Adequate health support Trust in healthcare professionals Distrust in healthcare professionals
Social Relations	31	286	Relationship with the loved one	27	177	Putting your loved one first Valuing your own needs Maintaining and stimulating your loved one’s autonomy Conflictuality Creating moments of sharing Lack of sharing Empathy and understanding
			Personal Relationships	16	26	Isolation Creating new social relationships Maintaining social interactions
			Social Support	20	67	Help and support from peer group Help and support from family, friends Loneliness
			Respected by others	10	16	Lack of understanding Understanding from others

the correct calorie intake. It was also difficult for carers to administer meals, especially considering that 39% ($n=12$) had to feed their loved ones:

“When you feed a person with dysphagia, she cannot control well the amount of food he can swallow ... when you have to feed her, it happens that you are in a hurry, that you may have to go back to work and in the end it is complicated” (husband, ALS).

In addition to fatigue, respondents reported difficulties in getting enough rest under the sub-theme of “Sleep and rest” (20%, $n=6$) due to the necessity to care for their family members during nocturnal hours: “He frequently had to cough, especially at night, when he experienced difficulty swallowing his saliva” (wife, stroke).

Furthermore, in the sub-theme “Physical pain and discomfort”, a minority of caregivers (13%, $n=4$) reported experiencing pain caused by having to position their loved ones correctly for mealtimes: “In the last moments, even

lifting her during the meal was difficult, because in the end she didn’t even support herself on her legs, she was a dead weight; so, my back always hurt and I had to take paracetamol every night” (daughter, ALS).

The impact of dysphagia management on caregivers’ ability to go out to eat (independently or with the care recipient) was examined, revealing a wide range of experiences, that did not correspond to the severity of the dysphagia. Most participants reported a reluctance to leave their loved ones unattended or to eat in public due to difficulties in identifying appropriate dining venues, as highlighted in the “Mobility” sub-theme. This difficulty in eating out was compounded by the challenges associated with administering food, personalising the correct consistency of food, and managing signs of dysphagia:

“Eating at the restaurant has become more difficult. I’m thinking about the last time we went with her, it’s one of the first things you lose, even though I had bought the mini

blender, with the USB charger, so we could do it on our own” (daughter, PD).

Despite these obstacles, some of the caregivers (6, 19.4%) reported employing various strategies to ensure that they could continue to engage in shared experiences and social interactions: “We also take him out to eat sometimes, even if he gets dirty or makes a mess” (daughter, PD).

Regarding caregivers’ ability to maintain professional activity, we observed substantial variability. A significant proportion of participants ($n=16$, 51.6%) reported the need to reduce working hours and increase requests for days or hours of leave and/or holidays (“Work Capacity” sub-theme). However, in some cases, respondents even had to relinquish their professional commitments entirely in order to provide full care for family members, particularly women and when the care recipient was affected by neurodegenerative conditions characterized by multiple impairments and the need for continuous assistance. “So I had decided to stay at home [to take care of her], however, I liked my job, so, I missed it” (daughter, ALS).

Psychological State

The “Psychological state” theme encompasses information on the psycho-emotional impact caused by their loved one’s OD. Our findings revealed a wide range of both negative and positive emotions associated with the management of OD. All caregivers reported a variety of negative feelings, which are collated under the sub-theme “Negative emotions”. The majority of respondents ($n=23$, 74.1%) reported feelings of fear or worry associated with the signs (coughing, aspiration) and consequences (pneumonia, choking) of swallowing difficulties: “The main worry is the risk of pneumonia; I am aware that if they contract it, it could be highly dangerous” (wife, stroke). Furthermore, nearly a third of caregivers (32%, $n=10$) reported feelings of embarrassment at the prospect of dining out in public with their loved one, especially when the care recipient also had dementia or cognitive impairments and was unable to modify their behaviour: “Sometimes they would like to go out to eat ... I start to feel ashamed to go to restaurants with him, because he gets dirty, he can’t hold the cutlery properly anymore. It’s a disaster” (wife, progressive supranuclear palsy). These caregivers further asserted that the discomfort and fatigue associated with swallowing difficulties have a more significant impact on their well-being than the pleasure of sharing a meal outside the home. Furthermore, 19% ($n=6$) of the respondents reported feelings of guilt surrounding the consequences of OD and its management, particularly in more severe cases or when the care recipient refused alternative feeding methods, including the development of aspiration pneumonia: “I have been caring for her for the past few months due to

loss of hand function. It is possible that I contributed to the development of pneumonia” (husband, ALS). The presence of dysphagia also frequently gave rise to sentiments of anger ($n=5$, 16.1%) and/or depression ($n=10$, 32.3%).

Conversely, many caregivers also reported positive feelings and coping strategies, which are collected in the sub-themes “positive emotions” ($n=11$, 35.5%), “resilience” ($n=9$, 29%), “hope” ($n=5$, 16.12%) and “self-esteem” ($n=10$; 32%). Hope, or the ability to perceive a potential course of action that may lead to a more favourable future, was expressed by one participant as: “I can only hope that this problem with swallowing can be resolved in my heart” (wife, stroke). In the subtheme of “resilience”, the caregivers described their ability to recover from adversity, uncertainty, and to adapt to stressful and changing life demands: “I was strong enough to face everything” (daughter, ALS). Also, in the subtheme “self-esteem”, the participants were able to identify positive qualities within themselves that enabled them to face the challenges related to the OD: “I was strong enough to face everything” (daughter, ALS). Alternatively, their optimism and contentment with their role were highlighted, as evidenced by their statement, “It did not burden me; rather, it brought me joy. I would have relinquished all else, even my employment.” (husband, ALS). In considering the care recipient demographics, these positive emotions did not appear to be related to the severity of dysphagia or the underlying pathology; rather, they were likely influenced by the caregivers’ personal characteristics.

The contrast between positive and negative emotions was further reflected in numerous carers’ accounts concerning their perceived efficacy in managing OD, as reported under the “Self-efficacy” sub-theme, where a spectrum of experiences were observed. On the one hand, the majority of caregivers ($n=25$, 81%) reported a sense of effectiveness in managing OD by applying techniques and practices to manage their care, but on the other hand, some of them ($n=21$, 68%) also reported a sense of ineffectiveness, in many cases in the face of the consequences of dysphagia: “I couldn’t get her to eat anymore; the last month has been just ice cream and puddings” (daughter, ALS). Variations in these experiences are influenced not only by the severity of the condition but also by several other factors, including the duration of contact with the care recipient, the caregiver’s relationship to them (e.g., spouse, daughter), and individual caregiver characteristics. In particular, wives and caregivers who have provided care over a longer period tend to report more positive experiences.

In the sub-theme entitled “Memory and Concentration”, a greater proportion of caregivers ($n=17$, 54.8%) reported an increase in concentration during mealtime, owing to the necessity of verifying the safety of swallowing and recalling the use of strategies for their loved ones: “the focus is

on him, on what he is eating, how he is eating it, how he is swallowing, how he is drinking” (father, stroke).

A range of beliefs and practices concerning meals and food and their impact on adherence to dietary recommendations were expressed by all caregivers and collated under the sub-theme of “Spirituality, religion, belief and value”. Some caregivers reported difficulty in adhering to dietary recommendations set by health professionals, citing the fact that food remains a source of pleasure for their loved ones, and the deprivation associated with this is perceived as having a greater impact than the potential for OD-related complications: “If he has to eat things, he doesn’t like to live two months longer, he might as well eat what he likes and live two months less” (wife, stroke). It is thus evident that meals and food play a pivotal role in the day-to-day life of people living with neurological conditions. A variety of accounts from caregivers expressed both their convictions and apprehensions concerning the necessity for alterations in consistency, and, in more critical instances, the potential transition to enteral nutrition, which is frequently perceived as “a therapeutic extreme”, “therapeutic stubbornness”, or “a cruelty”: “They had insisted so much on PEG but we never wanted it... I felt it was overkill at that point. My mum herself wouldn’t have wanted it. It’s still overkill, something a bit invasive” (daughter, ALS). On the other hand, some carers, especially those caring for care recipients with degenerative diseases, also reported a sense of relief when the PEG was placed: “When they placed the PEG tube, it was a real relief. If I had known earlier, I would have done it sooner. I no longer had to worry about how much he needed to eat, or spend so much time and effort on feeding him.” (wife, ALS).

Many caregivers adopted a fatalistic attitude or attempt to cope with the challenges of daily living: “This is the situation we are in, which is fine. When and if another circumstance arises, we will find a way to deal with that too” (daughter, ALS). Furthermore, a number of caregivers indicated that their religious beliefs provided them with a sense of support and assistance: “I must say that I also thank the Lord because there is also a hand from above to come, in my opinion” (wife, stroke).

Caregivers consistently endeavoured to maintain an equilibrium between the management of the care recipient’s dysphagia symptoms and their concurrent efforts to address the manifold limitations imposed by the disease. Caregivers’ approaches were characterised by a nuanced recalibration of priorities, with an emphasis placed on emphasising the multi-faceted nature of the challenge. This involved highlighting the intricacies involved in the management process itself and the consequential loss of autonomy experienced by the care recipient in numerous aspects of daily living: “Swallowing seemed to be the first thing to be controlled,

but now unfortunately it is the motor part” (husband, Huntington’s Disease). In addition, many carers report that it was not easy to understand the symptoms of dysphagia, to accept them and, in the case of degenerative diseases, to accept their worsening, to “sometimes trick themselves” into thinking that everything is fine: “She told me she was losing a lot [saliva] but it didn’t seem that much to me, seeing other patients it didn’t seem that bad to me...” (husband, ALS).

Accordingly, the sub-theme “Life Satisfaction” captured a spectrum of caregiver experiences, highlighting the variability in adaptation to caregiving demands. While a substantial proportion of caregivers ($n=10$, 32%) reported a deterioration in their quality of life, a smaller subset ($n=4$, 13%), especially in the case of stroke, were able to establish a new equilibrium: “We had to adapt to a new daily reality, but we were able to do that” (daughter, stroke).

Environment

The third domain concerns the “Environment”, defined as the set of all factors external to the individual (environmental, physical, health, etc.) that contribute to the sense of safety and physical security, to the perception of the degree of freedom and possibility of leisure (WHO, 2006).

The sub-theme “Access and Quality of Care” emerged as a prominent topic among all caregivers, highlighting substantial variability and divergent experiences in the provision and accessibility of care. Almost all caregivers emphasised the inadequacy of health support, the lack of home care services, and psychological support and information for managing dysphagia: “lack of communication, lack of information, lack of clarity of what the devices, the parts, for which one is tossed around a bit here and there” (mother-in-law, ALS). In addition, a small proportion of caregivers ($n=5$, 16.1%) expressed concerns regarding the professional caregivers’ levels of preparation and attentiveness: “During mealtimes, he places his mobile phone on my father’s leg and, while he provides him with a bite to eat, he engages in activities such as watching videos, listening to music, and occasionally playing music for him at specific times” (son, atypical parkinsonism). However, a third of the sample of carers ($n=10$, 32.2%) reported trust and appreciation of health professionals and said they particularly appreciated being actively involved in rehabilitation sessions: “In my opinion, the one who really has it all figured out is the carer, who, being with her breakfast, lunch and dinner, manages all these cares” (daughter, atypical parkinsonism).

The absence of a functional healthcare system that was able to provide adequate support to caregivers has led to an increased reliance on private healthcare services for many of the caregivers, as evidenced by the sub-theme “Financial

resources”: “The financial commitment is already substantial, including physiotherapy, speech therapy, a carer, and other private services” (daughter, atypical parkinsonism).

In light of the necessity to acquire “strategies”, “manual skills” and “knowledge” for the management of dysphagia, all caregivers reported quotes within the sub-theme “Learning and Skill Training”, thereby underscoring the significance of training by a healthcare professional, as well as the value of self-learning: “As a housewife, I did everything with experience as a housewife” (wife, stroke). However, as their proficiency grew, they began to train other caregivers or carers: “When swallowing difficulties appeared, I gave suggestions so that complications could be avoided” (son, atypical parkinsonism).

The sub-theme “Recreation” highlighted considerable variability in caregivers’ experiences. Approximately 20% of the caregivers ($n=6$, 19.6%) reported that they no longer have time for themselves and their hobbies, particularly in cases involving more complex or neurodegenerative disorders: “Progressively the mealtime became one of the worst times of the day, ... it did not allow for other things to be done” (husband, ALS). However, a significant proportion of caregivers ($n=9$, 29%), especially the youngest, reported that they have succeeded in organising themselves to maintain their activities: “I try to carve out some space for myself. Maybe I go out to dinner with my friends” (wife, PD). Overall, these findings suggest that age and the availability of a wide family and social support network played a key role in caregivers’ ability to maintain personal activities, independent of the severity of dysphagia.

In the subtopic entitled “Home Environment”, a single caregiver disclosed that he adapted his residence to enable autonomy and management of his wife, including while feeding, by establishing a designated station: “So we created a station where she stayed for hours, where she had the computer, the telephone and water at her disposal; at first she poured it herself, then when she was no longer able, I prepared two full glasses for her” (husband, ALS).

Social Relations

The fourth theme pertains to “Social relations”, defined as the connections between individuals who engage in recurrent interactions and are perceived to possess personal significance (Bandeira et al., 2018). All subthemes within this domain revealed a wide spectrum of experiences, reflecting considerable variability among caregivers.

The majority of caregivers ($n=27$, 87%) addressed the sub-theme of “Relationship with the loved one”, i.e., the influence of illness and OD on the care recipient-caregiver dyad. The majority of the interviewees dedicate their day-to-day life to their care recipient ($n=16$; 51.6%): “He can

no longer do even the simplest things; we have to take care of him” (father, stroke). However, one caregiver reported a necessity to “establish barriers” and assign primacy to her own needs (wife, PD). A significant proportion of the interviewees ($n=25$, 81%) reported that difficulties in adapting to the dietary restrictions and behavioural adaptations required by the presence of dysphagia led to moments of conflict: “Food was one of the things we quarrelled about the most because it was tiring for me, all this work that ended up in “I don’t like it”, “it’s not good”, “I don’t want it”” (wife, ALS). Conversely, caregiving was also reported to foster a strengthened relationship, creating moments of sharing ($n=8$, 25.8%) and also increasing empathy and understanding ($n=19$; 61.3%): “I went to live alone, but I used to spend my lunchtime at my mother’s house” (daughter, progressive supranuclear palsy).

Variability in caregivers’ narratives appeared to be shaped not only by the severity of dysphagia but also by additional factors. The presence of cognitive impairments in the care recipient can increase the need for supervision and reduce opportunities for reciprocal communication, making caregiving more burdensome and less relationally rewarding. Similarly, the type of caregiver-care recipient relationship plays a significant role: spousal caregivers often experience a sense of shared history and mutual dependence that can enhance moments of connection, whereas adult children may face greater tension between caregiving responsibilities and personal autonomy. Together, these factors suggest that the relational benefits of caregiving are not uniform, but instead emerge from a complex interplay between the care recipient’s clinical condition and the pre-existing emotional and social dynamics within the dyad.

Concerning the sub-theme of “Personal relationships”, many caregivers reported experiencing feelings of isolation due to the OD of their care recipient. The meal had lost its connotation as a moment of sharing and social interaction, especially in situations involving many people: “The meal, from being a social occasion, had become an individual moment” (mother-in-law, ALS). Some caregivers asserted that the frequency of shared meals has diminished due to a reluctance to cause discomfort to family and friends: “When friends came, he usually ate earlier because the prospect of coughing in front of others was disagreeable for them” (wife, ALS). Conversely, nearly a quarter of caregivers ($n=7$, 22.5%) reported that friends and relatives adapted to the care recipient’s difficulties, either by modifying the menu for everyone or by preparing different dishes so that the care recipient could eat together with them: “Even if he couldn’t eat, we would still get together and he would get the pudding, yoghurt or fruit” (wife, stroke). It is noteworthy that one younger caregiver reported that the illness and the presence of OD had facilitated the emergence of new

relationships: “Dysphagia made me meet people in the same condition as my husband...when I meet people who are facing similar difficulties, I approach them with all my heart” (daughter, supranuclear bulbar paralysis).

With regard to the sub-theme of “Social support”, approximately 50% of the sample ($n=15$) reported that they had the possibility of receiving support from friends and family to assist their loved ones. This support was regarded as a helpful coping strategy, as illustrated by the following statement: “I am fortunate to have the support of my brother” (wife, Lewy body dementia). A minority of caregivers ($n=6$, 19.4%), particularly those caring for individuals with rare or degenerative disorders, also reported on the role of associations and peer groups in facilitating the dissemination of information, as well as providing a source of emotional support: “[the caregiver group] helped me a lot, because there were times when it was really impossible to survive the emotional load” (daughter, supranuclear bulbar paralysis). Notwithstanding the documented evidence of support and emotional resonance, nearly half of the caregivers ($n=14$; 45.2%), particularly the oldest and those caring for recipients with cognitive impairments, reported experiencing feelings of loneliness.

In accordance with the aforementioned evidence, and as emphasised in the sub-theme entitled “Respect from others”, caregivers ($n=9$, 29.0%) reported a paucity of understanding and empathy from the general population. Those who do not care for a person with dysphagia have been reported to struggle to comprehend the caregiver’s needs and sacrifices: “I did not find much understanding for myself” (wife, supranuclear bulbar paralysis). Concomitantly, relatives and friends encounter difficulties in comprehending dysphagia management and occasionally experience feelings of embarrassment when attending meals due to alterations in consistency or strategies: “I am reminded of a dinner with maybe other family members, friends and relatives felt in awe” (daughter, supranuclear bulbar paralysis). Only three young caregivers reported feelings of understanding and respect from the social context: “There was a local who knew us well, they knew his problems, so, let’s say, it was no problem to go there” (daughter, Lewy body dementia).

Discussion

This study aims to explore the lived experiences—both positive and negative—of individuals caring for family members with oropharyngeal dysphagia (OD) across a range of neurological conditions and varying severities of dysphagia. Drawing on the Caregiver Quality of Life Framework (Martin et al., 2021), the findings indicate that caregivers

face daily challenges spanning multiple domains, including physical, social, and psychological aspects, as well as factors related to the broader environmental context. Despite these difficulties, participants also identify personal, social, and contextual resources, as well as positive experiences associated with their caregiving role.

The sample demographics reflected broader caregiving trends (Colombo et al., 2011), with predominantly older female caregivers (mean age >65) providing care for spouses or parents. These demographic characteristics likely contribute to the physical strain reported by participants; however, fatigue and discomfort were not solely attributable to dysphagia management but also reflected the broader complexity of care recipient disabilities. Consistent with previous literature (Lisiecka et al., 2020), caregivers frequently experience exhaustion and sleep disturbances, often linked to the management of dysphagia, suboptimal handling of secretions, and the physical demands of care recipient positioning and mobilization, which in some cases necessitate pharmacological intervention.

Reinforcing Existing Evidence

This study also supports existing evidence showing that meal preparation is perceived by caregivers as a lengthy and demanding task requiring substantial adjustments to daily routines (Robinson et al., 2022; Johansson & Johansson, 2009). Caregivers frequently have reported difficulties in identifying appropriate food consistencies and selecting appetising options, reflecting challenges previously documented in oncology (Nund et al. 2014b; Patterson et al. 2013) and stroke-related research (Robinson et al., 2022). Ensuring adequate caloric intake constitutes an additional burden, with many caregivers adapting meals by incorporating protein-rich or otherwise nutrient-dense foods (Shune & Namasivayam-MacDonald, 2020).

Significant modifications to mealtime routines are commonly reported, consistent with prior literature (Howells et al., 2021): caregivers described the need for continuous supervision, the use of verbal cues, and adaptations to eating utensils to support safe swallowing. Many sought to minimise distractions by creating quieter eating environments, consequently diminishing the social and convivial aspects traditionally associated with shared meals (Ninfa et al., 2021). In line with previous findings (Johansson & Johansson, 2009; Penner et al., 2012), some caregivers avoid eating in the presence of their loved ones to prevent distress when the care recipient was unable to consume the same foods. Accordingly, mealtimes often cease to function as opportunities for social interaction, with family members unable to eat together or partake in dining out (Miller et al. 2006; Nund et al. 2014b).

Social isolation emerged as a significant theme: many caregivers no longer shared meals with others, avoided eating out (Miller et al., 2006) and withdrew from social events where food was central (Nund et al. 2014b; Ninfa et al., 2021). Only a minority of caregivers successfully maintain social engagement by adapting to the challenges posed by dysphagia, reflecting a sense of social “loneliness” within the caregiving context (Nund et al. 2014b; Ninfa et al., 2021). In the present study, these differences in experience may be influenced not only by the severity of dysphagia but also by the overall health status of the care recipient, including comorbidities, cognitive impairments, and functional limitations, which increase the complexity of caregiving. Caregiver-related factors such as age, prior caregiving experience, personal resilience, coping strategies, and psychological characteristics further shape how challenges are perceived and managed. For example, older caregivers or those with limited prior experience may find mealtime supervision and nutritional management particularly burdensome, whereas caregivers with greater self-efficacy or familiarity with care routines may adapt more effectively. Social, cultural, and environmental factors, including the availability of external support networks, household resources, and societal expectations regarding caregiving roles, may also modulate these experiences, highlighting the multifactorial nature of caregiving in the context of dysphagia. Despite these challenges, participants consistently emphasized the importance of social support, with some participating in self-help groups that facilitated information exchange, emotional expression, and peer support (Koster et al., 2023).

OD also impacted caregivers’ occupational functioning, leading to reduced working hours or increased leave requests, consistent with evidence of decreased productivity among substantial informal caregivers (Patterson et al., 2013; Wolff et al., 2016).

The impact of OD on relationships with loved ones is also a salient theme. Caregivers tended to prioritise the care recipient’s needs over their own. However, in contrast to the observations reported by Shune and Linville (2019), dietary and behavioural modifications during mealtimes are not associated with the emergence of conflicts with the care recipients. In fact, the majority of participants noted that sharing such a crucial experience with their loved ones could strengthen their bond and foster a sense of empathy and mutual understanding. Also in this case, it is possible that the variability in caregivers’ experiences is only partly related to the severity of dysphagia, and is further influenced by factors such as the cognitive abilities of the care recipient, the nature of the caregiver–care recipient relationship, and the caregiver’s personal characteristics.

Emotionally, caregivers experience fear, anxiety, uncertainty and a sense of inadequacy regarding their responsibility for safe and adequate nutrition (Nund et al. 2014b; Penner et al. 2012). Additional negative emotions included guilt for consuming foods that their loved one is unable to eat, uncertainty about how to act in emergencies (e.g., choking), and frustration over the continuous monitoring of their loved one’s health and nutrition (Miller et al., 2006; Patterson et al., 2013). The mealtime routine has been found to evoke embarrassment and shame among caregivers (Howells et al., 2021) and can generate significant stress due to the intensive care required, as well as sadness associated with the care recipient’s suffering. These factors may contribute to an increased presence of depressive mood (Schulz & Sherwood, 2008). Consequently, these negative emotions can lead to a decline in quality of life (Arslan et al. 2017; Nund et al. 2014b).

Relational dynamics varies; while mealtime modifications occasionally generate conflict (Shune et al., 2019), many caregivers report that the shared experience of illness strengthened their emotional bond and enhanced mutual understanding.

Contributions of current study

Beyond confirming well-established challenges, this study also introduces several novel aspects. Firstly, departing from the notion of caregiving burden, some participants also report positive feelings, hope, acceptance and resilience and identified some positive aspects of their character. In a minority of cases, caregivers even establish a new balance and regained a sense of normality. While this perspective is relatively novel in the context of caregivers of individuals with OD, it aligns with the findings of Charenkova and colleagues (2023), who emphasised that for many caregivers, the satisfaction derived from their role outweighs the challenges they encounter in caregiving. The presence of self-esteem/self-efficacy, resilience, hope and optimism is of great importance and highlights some key elements of the higher-order construct of psychological capital, a collection of healthy psychological states that enhance well-being and performance (Luthans et al., 2007). The term encompasses the four key components previously cited, which work together synergistically. Empirical evidence has demonstrated that the elements of psychological capital facilitate the maintenance of composure in high-pressure environments and reduced stress levels when confronted with everyday challenges (Chiracu et al., 2023; Xin & Li, 2023). Thus, these individuals manifest elevated levels of psychological health and demonstrate enhanced performance in their responsibilities. Research has also demonstrated that the components of psychological capital can positively impact

well-being and quality of life (Chiracu et al., 2023; Xin & Li, 2023). While it is acknowledged that family caregivers shoulder the responsibility of care and encounter adverse consequences, in our study numerous caregivers adopted positive coping mechanisms that appeared to enhance their quality of life. Consequently, it may be beneficial for health care providers to consider the psychological capital of family carers, assess it and develop interventions to maintain positive coping strategies.

Second, our study underling the role of religious and spiritual coping strategies and that carers tend to prioritise maintaining their loved one's quality of life when making decisions about food and dietary restrictions (Johansson & Johansson, 2009). In a considerable number of cases, an analysis of caregivers' beliefs and values has provided a comprehensive understanding of the underlying factors that contributed to suboptimal adherence to therapeutic guidelines. Approximately one-third of participants cared for individuals partially or fully fed via percutaneous endoscopic gastrostomy (PEG), expressing diverse perspectives regarding its use. While literature indicates that PEG management can heighten caregiver stress due to balancing choking risk and care recipient preference (Bentur et al., 2015; Habermann & Shin, 2017), caregivers of individuals with degenerative diseases have reported greater ease in meeting nutritional needs via PEG, in contrast to caregivers of individuals with acute-onset dysphagia, who experienced challenges with enteral nutrition therapy. This discrepancy likely reflects differing perceptions of PEG permanence, with acceptance of long-term PEG use facilitating more positive appraisal. Many caregivers indicate that PEG would only be considered when essential for maintaining well-being, reflecting a form of "therapeutic stubbornness," consistent with findings in motor neuron disease populations (Stavroulakis et al., 2014).

In other cases, caregivers exhibit fatalistic attitudes or reported that their religious beliefs facilitated coping with daily life. For some interviewees, their religious faith are also supportive in the daily management of their loved one. Some interviewees report that seeing certain aspects as inescapable (e.g., death or pneumonia) enabled them to live with the presence of dysphagia. This phenomenon has been only minimally investigated in the extant literature on caregiver support and dysphagia management (Padilla et al., 2019), and is worth continued exploration. It is noteworthy that some caregivers reported instances of symptom denial and non-acceptance. For some, it was challenging to acknowledge the presence of dysphagia, and, particularly in cases of degenerative diseases, its deterioration to the extent of denying the progression of the condition.

A third contribution relates to caregivers' capacity for learning strategies, knowledge and skills to manage OD

and mealtime. While participants value the guidance provided by speech therapists (Howells et al., 2021), many also develop independent, experience-based strategies for managing dysphagia, with some attaining sufficient confidence to support other caregivers.

This finding highlights the capacity for learning and adaptation among caregivers facing particularly complex and multifaceted challenges, thereby extending the existing literature on caregiving, and specifically on caregivers of neurologic patients with dysphagia. Unlike general caregiving contexts, these caregivers must manage the progressive burden of the care recipient's condition, navigate the shrinking relational space within the dyad, and cope with the loss of social interactions around shared meals—a culturally significant aspect of life in Italy. Their adaptive capacity is further shaped by difficulties in accessing healthcare services, limited professional support, and challenges in obtaining adequate information about oropharyngeal dysphagia (OD) and its management (Ninfa et al., 2021). Participants also emphasize the need for psychological support and psychosocial interventions to facilitate coping, communication, and problem-solving (Glajchen, 2004). The caregiving process is inherently time-consuming, and for degenerative diseases, this time commitment increases concomitantly with the progression of the disease (Galvin et al., 2018). For instance, respondents report that their time is distributed between caregiving duties, professional obligations, and familial demands (Lisiecka et al., 2020; Holkham & Soundy, 2018), which implies a dramatic decrease in the amount of time they were able to devote to themselves.

Furthermore, the majority of caregivers report a need to expand the home support network (Nund et al., 2014b) to train the formal live-in caregivers in the management of dysphagia. Despite the central role plays by formal live-in caregivers, many of the participants in this study perceive them as inadequately prepared to assist their loved ones, inattentive to recommended strategies, and unaware of the associated challenges. This finding emphasises the necessity for a comprehensive approach to the care of individuals with OD, which should extend beyond the care recipient and their informal caregiver to include structured and adequate training for formal live-in caregivers, a role that is often overlooked. The inadequacies of the public health system also result in a significant number of our caregivers resorting to the private healthcare system for rehabilitative therapy and medical examinations, or the purchase of prescription medications and special foods. Consequently, the majority of respondents indicate that the financial obligations associated with the management of OD, and more broadly, the disease itself, have had a significant impact on their lives (Wolff et al., 2016).

Clinical implications

Caregivers of individuals with neurogenic dysphagia face significant clinical and psychological challenges that extend beyond the technical aspects of safe feeding. The urgent need for structured training programs—including food texture modification and safe meal administration—has been highlighted not only for informal caregivers but also for catering and hospitality staff, to foster inclusive dining environments (Pizzorni, 2017). Yet, caregiving is not limited to practical skills: the evolving nature of dysphagia requires ongoing support, practical tools, and monitoring strategies to reduce stress and uncertainty. Acceptance of the condition is often gradual, and conflicts may arise between caregivers and care recipients, underscoring the importance of psychological interventions that address both individual well-being and dyadic interactions (Yi et al., 2024). Evidence suggests that supervised support groups led by specialists can provide opportunities for emotional expression, peer learning, and skill development, thereby strengthening caregiver resilience (Yi et al., 2024). Moreover, understanding caregivers' beliefs and practices regarding dietary and behavioral strategies is essential, as personalized guidance increases adherence and improves daily care. Overall, these findings emphasize the necessity of a multidisciplinary, family-centered approach that integrates practical training, mental health support, and continuous monitoring to enhance caregiver resilience, reduce relational conflict, and improve care recipient outcomes.

Limitations and future directions

The present study is not without its limitations. The primary limitation is the selection bias inherent in the convenience sampling method, which may have excluded a substantial number of potential participants. Furthermore, it is possible that caregivers who consented to participate were those who perceived dysphagia to have a particularly significant impact on their daily lives. Future research should aim to increase the sample size to ensure greater variability and diversity of experiences and perspectives. Another limitation is the self-report bias associated with asking participants to recall and describe personal memories, emotions, and psychological states following the onset of dysphagia in their loved ones. Consequently, the possibility of personal biases and potentially unreliable self-reports must be acknowledged.

With regard to sociocultural and environmental factors, all participants reside in Italy, and the majority of caregivers enrolled are female. Although this finding is consistent with previous research showing that women are more likely than men to assume primary caregiving responsibilities and experience greater health-related burden, the observed

gender imbalance may be influenced by Italian cultural norms and could have affected the study results. Filial obligation and cultural values play a central role in motivating care, particularly for elderly parents or spouses, with caregiving often perceived as a moral duty and an expression of family loyalty (Di Rosa et al., 2023; Duxbury & Higgins, 2018). Moreover, the enduring influence of Catholic cultural traditions reinforces intergenerational support and the expectation that family members—especially women—assume the primary caregiving role (Albertini & Pavolini, 2017). Consistently, a meta-analysis reported that female caregivers of persons with dementia experience significantly higher caregiving burden than males (Cohen et al., 2023). Nevertheless, recent studies indicate that older male caregivers, particularly husbands caring for their wives, also undertake substantial caregiving tasks, including personal care and household management, while adapting to changes in marital roles and identity (Sanders & Power, 2009; Russell, 2001). Future research should explore gender differences in the impact of caregiving for specific conditions, such as dysphagia, to better inform tailored support interventions for both male and female caregivers.

Also, in Italy, the National Health Service provides universal coverage, offering access to primary care, specialist consultations, and hospital services. However, while formal healthcare services are widely available, the responsibility for day-to-day care of elderly or chronically ill family members often falls on informal caregivers, who may lack adequate training or support (Lamura et al., 2015). Therefore, conducting interviews with participants residing in different countries could yield divergent comments and suggestions.

Finally, the diagnosis of neurogenic OD is shared by all participants but derives from a heterogeneous range of diseases. It is acknowledged that diverse pathophysiological mechanisms and disease stages can result in varying degrees of OD, with consequent variations in the impact on daily activities and social participation. Whilst a quantitative analysis of the differences in reported themes according to diagnosis, severity of OD and onset of OD is beyond the scope of the present study, it is observed that the presence of a neurodegenerative disease or not (stroke or TBI) may have an influence on caregivers' beliefs about, for example, the quality of life of their caregiver and may engender negative feelings (e.g., fear or worry). Despite the fact that the utilisation of interviews and qualitative instruments facilitates an in-depth perspective on the caregivers' experience, the development of an ad hoc questionnaire to evaluate the quality of life of caregivers of dysphagic care recipients would enable a more substantial comparison between diverse populations and facilitate the assessment of the impact of each domain on the individual, thereby promoting the implementation of ad hoc interventions. Future research

should investigate variations across different neurological conditions. Implementing a tailored measurement tool could enable systematic comparisons across caregivers, which is difficult to achieve using qualitative data alone. Overall, these results highlight the importance of identifying caregivers' challenges and strengths to inform interventions tailored to the specific needs of the family unit.

Conclusion

In conclusion, this study demonstrates the utility of the Caregiver Quality of Life Framework (Martin et al., 2021) in capturing the multifaceted impact of dysphagia on caregivers. Applying established frameworks for qualitative data analysis allowed the integration of participants' subjective experiences with theoretical and methodological constructs. The study not only expands current knowledge on the effects of dysphagia among caregivers of individuals with neurological diseases but also addresses gaps in the literature, including the reliance on small, homogeneous samples, exclusive focus on caregiving burdens, and underrepresentation of caregivers of individuals with neurodegenerative conditions.

Beyond the burdens of caregiving, participants report positive emotions such as hope, acceptance, and resilience, and identified strengths in their own character. They develop new strategies and behaviours, enhancing their self-efficacy in managing dysphagia and supporting their loved one's quality of life. Caregiving often strengthens the emotional bond with the care recipient, which frequently became a central focus of their lives. Despite the risk of social isolation, caregivers demonstrate adaptation and resilience, and engagement in self-support groups is highlighted as important for meeting both emotional and informational needs.

Nevertheless, several unmet needs are identified, particularly regarding healthcare system support. Caregivers report insufficient information, difficulties accessing services, navigating bureaucratic procedures, and ensuring continuity of care at home. These findings underscore the importance of raising awareness about dysphagia and the role of the multidisciplinary deglutology team, as well as providing practical guidance on daily management, including dietary advice, recipes, organisational strategies, and navigation of healthcare processes.

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Data Availability The datasets generated during and analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethical Approval All procedures performed in the study were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the University of Milan – Bicocca.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Consent to Publish All participants provided informed consent for their anonymized data and information to be published in this manuscript.

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