



Quality of life of persons with non oncological diseases and dysphagia that need palliative care

Qualidade de vida de pessoas com doenças não oncológicas, disfagia e necessidade de cuidados paliativos

Calidad de vida de personas con enfermedades no oncológicas y disfagia con necesidad de cuidados paliativos

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Abstract

Introduction: Oropharyngeal dysphagia impacts on quality of life of persons under palliative care. **Objective:** To discuss the literature about quality of life of adults and older people living with non-oncological diseases and oropharyngeal dysphagia with needs of exclusive or predominant palliative care. **Method:** we realized a integrative review in LILACS, SciELO and PubMed databases, in September 2023, using the descriptors “swallowing disorders” or “swallowing” and “palliative care” and “quality of life” - there were variations due to the search tools of each base. We included studies on this theme of any publication year or language, excluding those about only esophageal dysphagia and/or cancer patients. Other researches cited in these were also selected, checking the inclusion and exclusion criteria. **Results:** Initially the search returned 84 studies. After reading them, we selected five ones, three qualitative and two quantitative studies, two European and three Brazilian papers, published in the last decade. Two were indexed in PubMed (one of them also in SciELO), two in SciELO and LILACS and one, only in LILACS. **Conclusion:** The literature was scarce, with different methods and small samples, discussing a relationship between oropharyngeal dysphagia and altered quality of life, one of them suggesting a positive impact of speech therapy intervention. The need for palliative speech therapy care is evident, taking into account quality of life as a measure of the effects of intervention. More studies are needed

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Authors' contributions:

FPR: study conception, methodology, data collection, study outline, critical review and guidance.

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Received: 12/22/2023

Accepted: 02/06/2024



with better methodology so that it is possible to establish clinical guidelines in palliative speech therapy.

Keywords: Quality of Life; Deglutition Disorders; Adult; Aged; Palliative Care; Speech, Language and Hearing Sciences.

Resumo

Introdução: A disfagia orofaríngea impacta a qualidade de vida de pessoas sob cuidados paliativos. **Objetivo:** discutir a literatura sobre qualidade de vida de adultos e idosos com doenças não oncológicas e disfagia orofaríngea, com necessidade de cuidados paliativos predominantes ou exclusivos. **Método:** Realizou-se revisão integrativa de literatura, buscando-se artigos nas bases LILACS, SciELO e PubMed, em setembro de 2023, com os descritores “transtornos da deglutição” ou “deglutição” e “cuidados paliativos” e “qualidade de vida” - houve variações devido às ferramentas de busca de cada base. Incluíram-se estudos de qualquer ano ou idioma, sobre disfagia orofaríngea e qualidade de vida em adultos e/ou idosos com necessidades de cuidados paliativos, excluindo-se aqueles exclusivamente sobre disfagia esofágica e/ou pacientes oncológicos. Selecionaram-se, também, outras pesquisas referenciadas nos estudos lidos, incluindo-se as que atendessem aos critérios de inclusão e exclusão. **Resultados:** Encontraram-se inicialmente 84 estudos. Ao final, incluíram-se cinco estudos, três qualitativos e dois quantitativos, dois europeus e três brasileiros, publicados na última década; dois indexados em PubMed (um deles também no SciELO), dois em SciELO e LILACS e um somente em LILACS. **Conclusão:** A literatura levantada mostrou-se escassa, com métodos diversos, amostras pequenas. Todos demonstraram relação entre disfagia orofaríngea e qualidade de vida alterada, um deles sugerindo impacto positivo da intervenção fonoaudiológica. Evidencia-se necessidade de cuidado fonoaudiológico com foco na qualidade de vida, a qual possibilita avaliação dos efeitos da intervenção. Necessitam-se mais estudos e com metodologia mais robusta para que seja possível estabelecer diretrizes clínicas na fonoaudiologia paliativista.

Palavras-chave: Qualidade de vida; Transtornos de Deglutição; Adulto; Idoso; Cuidados Paliativos; Fonoaudiologia.

Resumen

Introducción: La disfagia orofaríngea perjudica la calidad de vida de personas en cuidados paliativos. **Objetivo:** discutir la literatura sobre la calidad de vida de adultos y personas mayores con enfermedades no oncológicas y disfagia orofaríngea necesitando de cuidados paliativos predominantes o exclusivos. **Método:** se realizó revisión integrativa de la literatura, buscándose artículos en LILACS, SciELO y PubMed, en septiembre de 2023, con los descriptores “transtornos de la deglución” o “deglución” y “cuidados paliativos” y “calidad de vida” - hubo variaciones debido a las herramientas de búsqueda disponibles en cada base. Se incluyeron estudios sobre la temática de cualquier año o idioma, excluyendo aquellos exclusivamente sobre disfagia esofágica y/o pacientes con cáncer. Durante la lectura de los estudios incluidos, se seleccionaron otros citados en ellos, verificándose los criterios de inclusión y exclusión. **Resultados:** Inicialmente se encontraron 84 estudios, dos cuales se incluyeron cinco, tres cualitativos y dos cuantitativos, dos europeos y tres brasileños, de la última década; dos indexados en PubMed (uno de ellos también en SciELO), dos en SciELO y LILACS y uno sólo en LILACS. **Conclusión:** La literatura fue escasa, con diferentes métodos y muestras pequeñas. Todos discutieron la relación entre la disfagia orofaríngea y la calidad de vida alterada, y uno de ellos sugirió impacto positivo de la intervención logopédica. Es evidente la necesidad de logopedia paliativista, teniendo en cuenta la calidad de vida como medida de los efectos terapéuticos. Se necesitan más estudios con una metodología mejor para que sea posible establecer guías clínicas en logopedia paliativa.

Palabras clave: Calidad de Vida; Trastornos de deglución; Adulto; Anciano; Cuidados Paliativos; Fonoaudiología.



Introduction

Due to the aging population, the rise in non-communicable diseases and the recent emergence of COVID-19, the demand for palliative care has rapidly increased¹, with a projected doubling by 2060². Data from the World Health Organization in 2020¹ showed that over 70% of individuals with documented palliative care needs have non-oncological diseases, primarily cerebrovascular diseases, Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS), and major neurocognitive disorder (dementia).

Palliative care constitutes a multiprofessional approach to prevent and alleviate suffering, identifying, assessing, and treating pain and other physical, psychological, social, and spiritual issues³. Existing literature suggests that individuals under palliative care are more likely to experience oropharyngeal dysphagia⁴⁻⁵, alterations in the transport of food, secretions, liquids, or saliva from the mouth to the transition from the pharynx to the esophagus. The significance of this lies in its association with nutrition, hydration, and pulmonary health, as well as its role in pleasure, socialization, self-image, and comfort, particularly towards the end of life⁶⁻⁷. Palliative care plays a relevant role in improving quality of life⁸, defined as “an individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns.” This is achieved by enhancing individuals’ capacity to achieve personalized goals, such as symptom control and social support, while establishing realistic expectations through effective communication⁸.

Therefore, to ensure an improvement in the quality of life (QoL), it is essential to understand how it is affected by the conditions individuals under palliative care live with, including oropharyngeal dysphagia.

A recent study involving 81 adult and elderly patients living with cancer under palliative care compared the quality of life between those with and without oropharyngeal dysphagia, utilizing the Quality of Life in Swallowing Disorders questionnaire (SWAL-QOL)⁸. Significant differences were found in the following domains: swallowing as a burden, desire to eat, meal duration, symptom frequency, food selection, communication, and mental health.

Based on the presented data and the lack of similar research in line with the objectives of our study, this study aims to discuss the literature on the quality of life in adult and elderly individuals living with non-oncological diseases and oropharyngeal dysphagia, requiring predominant or exclusive palliative care.

Material and method

An integrative literature review was conducted with the guiding question, “What is the quality of life of adult and elderly individuals living with non-oncological diseases and oropharyngeal dysphagia, with a focus on predominant or exclusive palliative care?” The search was performed in the Latin American and Caribbean Health Sciences Literature (LILACS), Scientific Electronic Library Online (SciELO), and PubMed databases in September 2023. In LILACS, the search key was: “transtornos da deglutição” or “deglutição” [Subject Heading] and “cuidados PALIATIVOS” [Subject Heading] and “QUALIDADE DE VIDA” [Subject Heading]. In SciELO, the search keys were: (transtornos de deglutição) OR (deglutição) AND (qualidade de vida) AND (cuidados paliativos); (deglutition disorder) OR (deglutition) AND (quality of life) AND (palliative care) OR (deglutition); (Trastornos de Deglución) OR (Deglución) AND (cuidados paliativos) AND (calidad de vida); (Trastornos de Deglución) OR (Deglución) AND (cuidados paliativos) AND (calidad de vida);

In PubMed, the search key used was (((deglutition disorder[MeSH Terms]) OR (“deglutition”[MeSH Terms])) AND (palliative care[MeSH Terms])) AND (quality of life[MeSH Terms]). It is important to note that different search keys were used due to the tools available on each database.

Inclusion criteria encompassed studies evaluating and discussing oropharyngeal dysphagia and quality of life in adult and/or elderly individuals with non-oncological diseases, without restriction on the publication year. Studies exclusively assessing esophageal dysphagia and/or individuals with cancer were excluded.

The definition of quality of life provided by the World Health Organization in the introduction of this study was considered, allowing the inclusion of studies evaluating any impact on the lives of

individuals under palliative care, regardless of the method used for assessment.

During the full-text reading of the studies that met the inclusion and exclusion criteria, to determine their inclusion in this review, additional research referenced in these studies was selected. These additional studies were also read in full to assess their potential integration into this review.

Results

Eighty-four studies were found based on the keywords used in the selected databases, and seven

were selected after reading the titles and abstracts. Three were duplicates, resulting in four unique studies. After reading them in full, one study was excluded as it focused solely on oncology patients. During this reading, two additional studies were identified in the referenced works, and their titles and/or abstracts indicated a possibility of inclusion in the research. Both were read in full, with one of them meeting the inclusion and exclusion criteria and being included in the research. Figure 1 shows the flowchart of study selection, providing detailed information on works included and excluded at each stage.

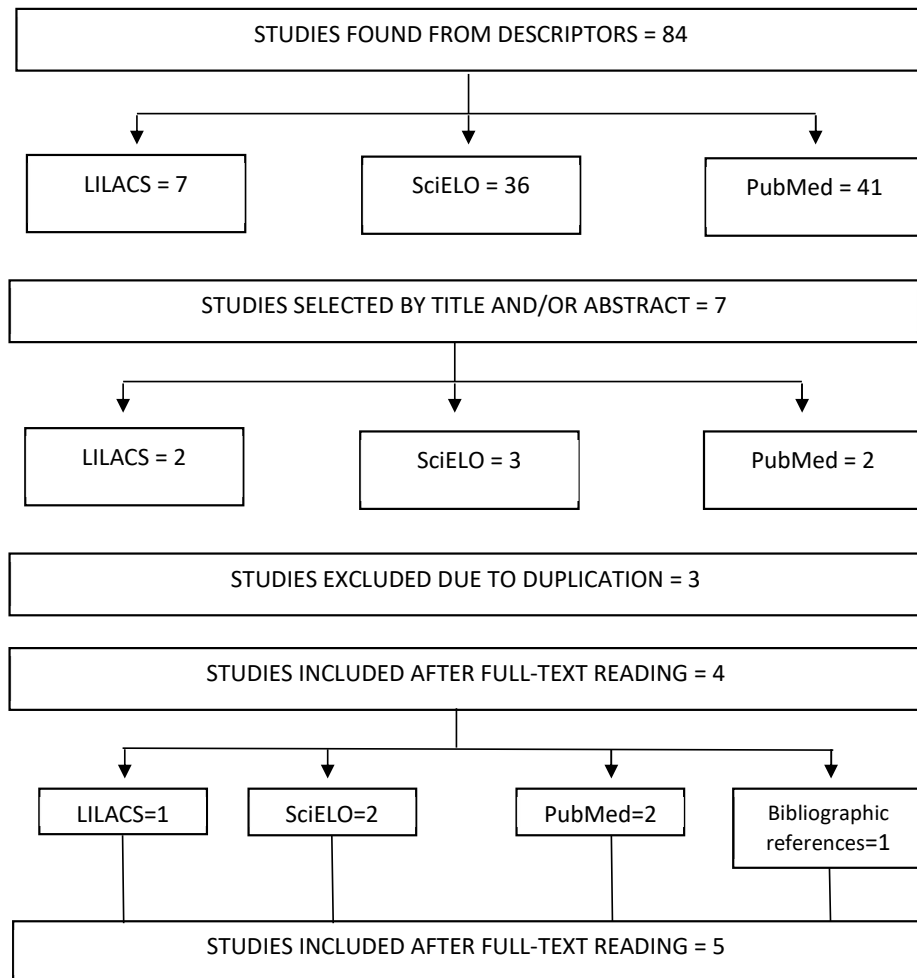


Figure 1. Flow chart of study selection

Consequently, five studies were included, comprising three qualitative and two quantitative studies, with two conducted in Europe (Italy and the Netherlands) and three in Brazil, all published in the last decade. Two were indexed in PubMed (one of them also in SciELO), two in SciELO and LILACS, and only one in LILACS.

All studies demonstrated a connection between oropharyngeal dysphagia and altered quality of life, with one suggesting a positive impact of speech therapy intervention.

The main data from each included study are presented in Chart 1.

Chart 1. Main information from the studies included in this review

Year	First Author	Country	Purpose	Participants	Methods	Main results
2014	Boogaardt H	Netherlands	To present the incidence of swallowing problems and related issues in individuals in the terminal phase of life (last 72 hours)	164 adults and elderly individuals at the end of life were monitored in home care, hospitals, and long-term care facilities	In a larger survey, data on swallowing (four questions, including difficulty swallowing, frequent coughing, loss of appetite, and issues with oral secretions), one on psychosocial function (scale of 0 to 10, where zero is the lowest and ten is the highest, respectively), and physical well-being (scale of 0 to 10) were selected. These were documented in writing by grieving family members and the nursing team caring for the person in their last 72 hours. In the medical records, diagnosis, age, and other data were selected.	Most participants (66%) were women, residing in long-term care facilities for the elderly (53%), with an average age of 76.5 years. 39.8% had non-oncological diseases. The majority (46%) of responding family members were children. Overall, the nursing team perceived less difficulty in swallowing than family members (78.7% versus 65.8%, respectively), with family members also considering it more severe than professionals ($p < 0.0001$). Individuals with non-oncological diseases had more difficulty swallowing (81.5% versus 79.5% according to family members [$p = 0.39$] and 76.5 versus 58.1% [$p = 0.3$] according to the nursing team (a statistically significant difference). Family members and the nursing team attributed an average of 4.9 and 4.5 to psychosocial well-being, 2.5 and 2.7 to physical well-being, with no statistically significant differences. Dysphagia was related to all other symptoms observed during the terminal phase of life in most patients in this study. There was a correlation between loss of appetite and physical well-being, and between swallowing problems, psychosocial and physical well-being, according to the nursing team's assessment. This latter correlation was also found in the assessment of family members. It is suggested that more specialized training for speech-language pathologists on the care and management of swallowing problems at the end of life is necessary. Furthermore, it is proposed that, specifically at the end of life, the impact of any interventions for these problems on the quality of life is minimal. Therefore, any proposed intervention should be proportionate to the level of suffering caused by the intervention.
2018	Luchesi K	Brazil	To discuss the speech-language pathology practice in dysphagia, focused on palliative care and quality of life in swallowing for patients with Amyotrophic Lateral Sclerosis (ALS).	Four cases diagnosed with ALS undergoing speech-language pathology and neurological follow-up at a tertiary hospital.	Data collection involved medical record review, classification of swallowing functionality using the Functional Oral Intake Scale (FOIS), ALS severity scale (EGELA), videofluoroscopic swallowing examination, classification of dysphagia severity using the Dysphagia Outcome and Severity Scale (DOSS), dysphagia quality of life questionnaire (SWAL-QOL), and structured interviews.	Patients presented a range from functional swallowing to mild to moderate dysphagia, with an impact on swallowing quality of life ranging from mild to moderate. There was no correspondence between the severity of dysphagia and quality of life. Other factors, such as communication, were intrinsically associated with swallowing quality of life. The cases perceived swallowing as a form of socialization or body maintenance. They reported feeling uncomfortable with exclusive alternative feeding and emphasized that oral food intake, even if minimal, purely for the pleasure of eating, would positively affect their quality of life. All expressed a preference for food to be offered at room temperature or warm. Emphasizing the importance of understanding patients' desires regarding their diet and the meaning they attribute to it, speech-language pathology practice can genuinely contribute to the individual's quality of life. It is believed that considering the multidimensional manifestations of ALS, the pursuit of quality of life based on palliative care principles and enjoyable eating experiences can positively impact disease progression.



Year	First Author	Country	Purpose	Participants	Methods	Main results
2020	Santos LB dos	Brazil	To characterize swallowing-related changes and the main speech-language pathology interventions in palliative care patients with oropharyngeal dysphagia.	Twenty patients admitted to the wards of a general hospital with exclusive SUS [Unified Health System] coverage in Florianópolis, Santa Catarina, Brazil. These patients were under palliative care, of both genders, aged 18 years or older, alert, and able to comprehend commands.	Data were collected from medical records, functional swallowing assessments based on prescribed diets and patient conditions, evaluating the efficiency of food bolus capture, lip seal, food bolus preparation, slow or adequate oral transit time, presence or absence of extraoral escape, and oral cavity residue after swallowing. Clinical signs of laryngeal penetration and/or laryngotracheal aspiration, such as cough, dyspnea, "wet" voice, throat clearing, and/or positive cervical auscultation, were also examined. The Functional Oral Intake Scale (FOIS) was used to assess feeding functionality. Speech-language pathology interventions adopted were described. Questions about patient particulars and comfort covered the topic of nutrition and inquired about the incidence of pneumonia during hospitalization, including whether the patient felt hungry or thirsty, expressed discomfort during or in the absence of eating, experienced respiratory discomfort or dyspnea during eating, and was satisfied with the food received during hospitalization.	The majority were male (13), with an average age of 75.5 years. The most common comorbidities were hypertension (35%), diabetes mellitus (15%), prior neurological events (15%), and chronic obstructive pulmonary disease (COPD) (10%). 25% were former alcohol consumers, and 20% were former smokers. The average length of hospital stay was 15 days. After this period, 55% passed away during hospitalization, and 45% were discharged. The consistencies used were liquid (55%) and honey-thick (50%). Prolonged oral transit time, oral cavity residue after swallowing, and "wet" voice after swallowing were observed in all consistencies. 85% were exclusively orally fed, 10% used nasoenteral tube (NET) in addition to oral intake, and 5% used exclusive NET. In the FOIS, 10% were classified at level 6, 50% at level 5, 25% at level 4, 10% at level 2, and 5% at level 1. The most commonly identified swallowing-related changes were clinical signs suggestive of lower airway penetration (laryngeal penetration and/or laryngotracheal aspiration), primarily for liquids, and alterations in the oral phase of swallowing for solid consistency. Through the satisfaction questionnaire, it was possible to identify that no individual developed pneumonia during hospitalization. 95% were satisfied with the served diet, including the 10% using nasoenteral tube (NET) and minimal oral intake. 70% reported hunger (all of whom were on oral feeding), while the 15% with NET claimed not to feel hungry. 60% reported thirst, including the 10% using NET. Among those orally fed, 15% reported discomfort in the absence of feeding, and 10% reported respiratory discomfort during feeding. The main speech-language pathology interventions performed included adjustments to the consistencies of prescribed diets during hospitalization and guidance on maneuvers for multiple swallows and effortful swallowing. The majority of patients maintained oral feeding throughout the hospital stay, respecting the patient's and family's preferences and ensuring a pleasurable experience. It is emphasized that caution is necessary when generalizing based on the results and conclusions of this study, as there was a small and heterogeneous number of participants.





Year	First Author	Country	Purpose	Participants	Methods	Main results
2018	Jacinto-Scudeiro LA	Brazil	To correlate the clinical findings of dysarthria, dysphagia, and cognition with the health decision-making process in a patient with a molecularly confirmed diagnosis of Ataxia Telangiectasia (AT) in palliative care at the end of life.	A 21-year-old male patient with 14 years of education, currently enrolled in higher education, diagnosed with AT at the age of 2, and wheelchair-dependent since the age of 10. The patient had dependence for activities of daily living and sought a speech-language pathology assessment reporting oral feeding across all consistencies, a history of recurrent bronchopneumonia (three hospitalizations in the past six months), and weight loss.	A clinical speech-language pathology assessment of dysarthria, dysphagia, and cognition was conducted. The following protocols were applied: Eating Assessment Tool (EAT-10); Questionnaire for self-perception of dysphagia and dysarthria; Radboud Oral Inventory Motor for Parkinson's disease (ROMP). Swallowing was clinically evaluated using the Northwestern Dysphagia Patient Check Sheet (NDPCS), objective swallowing assessment through video fluoroscopic swallowing study using the Rosenbeck scale, functional feeding assessment through the Functional Oral Intake Scale (FOIS), clinical assessment of dysarthria (evaluation of the five speech motor bases), cognitive screening (Mini-Mental State Examination), and cognitive assessment using the Montreal Cognitive Assessment.	In the EAT-10, the patient scored 15 (maximum score is 40 points, with a risk for dysphagia considered for patients ≥ 3 points). In ROMP, he scored 16 in the speech self-perception questionnaire (7 items, scored 1 to 5 points each, with one considered normal and five the worst score), 21 in swallowing (7 items, using the same scoring scale), and 14 in saliva (7 items, using the same scoring scale). In the NDPCS, he scored 20 points, and in this instrument, the patient's performance is scored in 28 items, with higher scores indicating greater severity of dysphagia. Notable items included a history of recurrent pneumonia, aspiration pneumonia, temperature spikes, ability to handle secretions, postural control, fatigue, apraxia of swallowing (except for following directions and swallowing saliva - all related to swallowing). He scored 8 on the Rosenbek scale, indicating a diagnosis of moderate to severe oropharyngeal dysphagia, and level 2 (dependent on an alternative route and minimal oral intake of some foods or liquids) on the Functional Oral Intake Scale (FOIS). Additionally, there was observed aspiration of saliva, liquids, and thick homogeneous pastes without benefit from airway protective maneuvers. In the dysarthria assessment, the patient had articulatory imprecision, distortions in consonants and vowels, and decreased speech rate with significant compromise to intelligibility, classified as ataxic dysarthria. In the Mini-Mental State Examination and Montreal Cognitive Assessment, it was identified that cognitive functions were within the normal range for age and educational level. A multidisciplinary discussion was conducted to determine the appropriate course of action, leading to the conclusion that the disease had significantly progressed. The patient's clinical condition contraindicated gastrostomy (permanent alternative feeding route), and the insertion of a nasogastric tube would be excessively invasive without benefits to his quality of life at that moment. The patient, who was oriented, maintained an active social life, and expressed the desire to continue with oral feeding, played a crucial role in this decision-making process. After a speech-language pathology assessment and discussion with the medical and nutritional team, as well as the patient and family, it was concluded that due to the considerable progression of the disease, the patient's clinical condition contraindicated gastrostomy and nasogastric tube placement, as these would be overly invasive procedures without clear benefits to his quality of life at that time. The patient, being oriented, actively engaged in social activities, and expressing the desire to maintain an oral diet, influenced this decision. Additionally, even with oral intake restrictions, the patient would continue to aspirate saliva, not eliminating the risk of aspirations and consequently, respiratory complications. Therefore, the decision was made to maintain an exclusive oral diet with a homogeneous paste consistency and nutritional supplementation. After one week, the patient expressed a desire to continue eating all consistencies, regardless of the risk of laryngotracheal aspiration, even while aware of the potential pulmonary complications. The joint decision-making process took place over five meetings, with an average duration of 45 minutes each. The first consultation involved the patient and mother, discussing the risks of maintaining an oral diet. The second and third consultations included the attending physician, the nutritionist, the patient, and the mother. These consultations focused on both the risks and the attempt to multidisciplinary align the patient's desires with clinical possibilities. In the last two consultations, only the mother attended, as the patient's clinical condition had worsened. At this end-of-life stage, she chose to prioritize her son's quality of life, despite being aware of the risks. The patient passed away 15 days after the last outpatient consultation. The discussion emphasizes that healthcare professionals, including speech-language pathologist, should approach therapeutic decisions with a fresh perspective, starting from the process of shared decision-making and informed choice. In palliative care, the concept of quality of life, a topic widely discussed, can be enhanced by involving the desires of patients and their families in choosing the path to be followed.

Year	First Author	Country	Purpose	Participants	Methods	Main results
2015	Veronese	Italy	To analyze the needs of individuals with neurodegenerative diseases in the city of Turin, Italy, and assess their perception of how specialized palliative care services could assist them.	Twenty-two severely affected adult patients with amyotrophic lateral sclerosis (ALS), motor neuron disease (MND), multiple sclerosis (MS), Parkinson's disease (PD), or multiple system atrophy (MSA) were included in the study. They were recruited from two reference institutions. Patients and their caregivers were identified through databases at two reference hospitals (neurological, pulmonary, and rehabilitation wards). These patients/caregivers were contacted by phone by a specialist physician who explained the research in detail. Additionally, focus groups were conducted with specialized medical professionals, including neurologists, rehabilitation specialists, physiotherapists, and speech-language pathologists. Due to organizational issues, nurses and general practitioners were not included. Both focus groups and interviews were recorded in video and audio, and field notes were taken.	Open interviews were conducted, prompting individuals to share their disease history, focusing on their major challenges across physical, psychological, social, and spiritual spheres. They were also asked about the type of assistance they would expect from a palliative care service.	Physical issues faced by the patients were widely reported. Specifically, all participants mentioned impaired movement and related symptoms (stiffness, tremors, and falls). Patients who could still walk highlighted reduced mobility, symptom fluctuation, and disease progression. Many of these patients report feelings of shame, a sense of incapacity, anxiety, and depression due to the loss of independence and consequently, the need for assistance. They describe high expenses associated with caregivers, social isolation, mobility issues, and isolation due to their illnesses. They express anger, a lack of control, and a need for spiritual support. Eighty-two percent of the patients experienced dyspnea or respiratory symptoms, with ten of them using mechanical ventilation (six non-invasive and four invasive, via tracheostomy). In 82% of cases, syndromic pain, painful muscle spasms, or cramps were identified. Despite the high prevalence, only two patients were receiving opioids for chronic pain, while one was taking medication for neuropathic pain. Many participants did not immediately recognize pain as a disease-related issue. Choking while consuming food or liquids, saliva aspiration, and nutritional problems were reported in 96% of the interviews. Nine patients were receiving nutrition and hydration through gastrostomy. Swallowing difficulties had a significantly negative impact on caregivers, forcing them to spend extended time with the patient and alter their food preparation habits. Aspiration episodes often led to aspirative pneumonia and subsequent hospitalization. There was no information on the awareness of the need for palliative care in patients with dysphagia. Professionals demonstrated an understanding of the burden on caregivers in physical, psychological, social, and spiritual aspects, as well as their inability to meet the needs of patients. They also confirmed difficulties in determining the number of people in advanced disease stages who might require specialized palliative care and their inability to continue caring for them in their clinics during these disease stages.

Discussion

The five included studies¹³⁻¹⁷ were published in the last decade (2014, 2015, 2018 [two studies], and 2020), which shows how the topic has been recently and sparingly discussed, in contrast to the high frequency of oropharyngeal dysphagia in individuals with non-oncological diseases¹⁰. As previously mentioned, these individuals represent the majority of those requiring palliative care². This scarcity directly impacts clinical actions, as quality of life is a fundamental aspect of palliative care, aiming to improve life quality by bridging the gap between expectations and reality¹¹⁻¹². This involves helping individuals “recalibrate” their expectations and addressing crucial domains as the disease progresses. In this context, important strategies include increasing one’s sense of identity, excellent symptom management, and functional improvement through rehabilitation¹¹, with a relevant role played by speech-language pathology⁴.

The relationship between a specific health condition and quality of life is indirect, extending

beyond physical symptoms to encompass physical and psychological comfort, living in a tranquil environment, experiencing pleasure, maintaining positive relationships with the medical team, family, and friends, maximizing independence, being respected as an individual, and feeling fulfilled by achieving life goals¹¹. The fact that the majority of studies¹⁵⁻¹⁷ was conducted in Brazil underscores the contribution of our country to the literature on this subject.

The sample size in the five studies was as follows: one individual¹⁷ (a clinical case study with a neurological disease), four individuals¹⁵ (clinical case studies), twenty individuals¹⁶ (descriptive quantitative study), twenty-two individuals¹⁴ (qualitative study with interviews), and 164 individuals¹³ (analytical study). Most of the patients included in the studies were aged sixty or older.

Family/caregiver participation was observed in three studies^{13-14,16}, with one of them involving nursing professionals¹³, and another including speech-language pathologists, neurologists, and other healthcare professionals¹⁴.



The sample included patients living with cancer in two studies^{13,16}, and in all studies¹³⁻¹⁷, there were patients with neurological diagnoses, comprising the entirety of diagnoses in three studies^{14-15,17}.

Two studies focused on hospitalized patients^{13,16}, with one of them also including patients receiving home care and long-term care facility assistance¹³, all in the end-of-life stage. In the other study¹⁶, all participants were hospitalized, and the majority was in the end-of-life stage. Three studies were conducted on patients in outpatient settings^{14-15,17}, with one of them involving an individual at the end of life¹⁷. In the other two¹⁴⁻¹⁵, this information was not specified, but in one of them¹⁴, the 22 participating patients were in an advanced stage of neurological disease. In the other¹⁵, the four participating patients, all with amyotrophic lateral sclerosis, had varied functional impairments resulting from neurological diseases.

In the two European studies¹³⁻¹⁴, oropharyngeal dysphagia was considered as reported difficulty swallowing by caregivers and/or care recipients. This report emerged spontaneously in interviews in one study¹⁴, while four specific questions were asked in the other¹³ – addressing difficulty swallowing, frequent coughing, loss of appetite, and issues with oral secretions. In the three Brazilian studies, it was diagnosed through speech-language pathology assessment¹⁵⁻¹⁷ and additionally through instrumental swallowing assessment in two of them^{15,17}.

Quality of life was assessed using instruments that investigate the impact of swallowing on life (Quality of Life in Swallowing Disorders - SWAL-QoL and Eating Assessment Tool - EAT-10) in two studies^{15,17}. In one of these studies¹⁷, there was also a mention that the choice for oral feeding by the patient and caregiver had been “for quality of life,” without referring to the instrument results and without specifying how this was evaluated in this particular circumstance. The SWAL-QoL was translated and validated in Brazil¹⁸. It relies on the quantitative measurement of reported outcomes provided by the patients themselves. These data are entered and evaluated on eleven different scales, structured through a scoring system ranging from “0” to “100”, where lower values represent poorer swallowing-related quality of life. Its development aims to be used in patients with dysphagia of different etiologies, contributing to monitoring changes in quality of life after therapeutic intervention.

The domains include “swallowing as a burden”, “desire to eat”, “eating time”, “frequency of symptoms”, “food selection”, “communication”, “fear of eating”, “mental health”, “social”, “sleep”, and “fatigue”. The Eating Assessment Tool (EAT-10) has demonstrated cultural equivalence for Brazilian Portuguese¹⁹. It was conceptually developed as a self-assessment instrument with ten questions about functionality, psychosocial impact, and physical symptoms that swallowing problems may have on an individual’s life. The person assesses how much each statement is a problem for them, choosing from 0 - when it is not a problem, 1, 2, 3, or 4 - when it is a significant problem. Among the questions are “my swallowing problem prevents me from eating out”, “my swallowing problem takes away the pleasure of eating”, and “swallowing stresses me out”. The maximum score is 40 points, considering patients with 3 points or more at risk for dysphagia.

Quality of life was assessed in two studies^{13,16} through questions formulated by researchers about the impact on life. In one¹³, participants were asked to rate “physical well-being” and “psychosocial function” on a scale of 0 to 10. In the other, questions were formulated about satisfaction with feeding, feeding as a form of socialization, and the unacceptability of not being able to eat orally¹⁶.

In the fifth study¹⁴, the investigation of quality of life occurred through open interviews where patients (and/or their caregivers) were asked to discuss the major difficulties faced in their experience with advanced neurological diseases and how specialized palliative care services could help. The interviews revealed the narration of dysphagia and its impact on life.

Although using different methods, all included studies demonstrated an association between oropharyngeal dysphagia and an impact on quality of life, either through assessment by care recipients¹³⁻¹⁷, caregivers and/or family members¹³⁻¹⁷, or professionals¹³⁻¹⁴. One study reported a positive impact on people’s quality of life after speech-language pathology intervention¹⁶, with 95% of individuals satisfied with their feeding despite adaptations.

Regarding the relationship between dysphagia and quality of life, the Brazilian study on four cases with amyotrophic lateral sclerosis¹⁵ found varying degrees of alteration in swallowing-related quality of life, ranging from mild to severe, with



no direct correlation between it and the severity of dysphagia. Other factors were intrinsically associated with swallowing-related quality of life, not just its functionality, such as communication. Participants attributed socialization and survival meanings to swallowing, expressing discomfort with exclusive alternative feeding. They reported feeling uncomfortable with exclusive alternative feeding and emphasized that oral food intake, even if minimal, purely for the pleasure of eating, would positively affect their quality of life.

The relationship between dysphagia and quality of life was not specifically assessed in the Brazilian study involving twenty hospitalized patients¹⁶. However, the study mentioned that palliative speech therapy intervention for swallowing care maintained a 95% satisfaction rate with the diet, including those using a nasogastric tube and minimal oral intake. The study reported additional aspects considered as “assessment of satisfaction with feeding”: no individual developed pneumonia during hospitalization, 70% of orally fed individuals reported hunger compared to 15% with nasogastric tube feeding, and 60% reported thirst, including 10% with nasogastric tube feeding. Of those orally fed, 15% reported discomfort when not eating, and 10% reported respiratory discomfort during meals. The authors indirectly addressed quality of life by stating that patients and family members had their wish to maintain oral feeding met during hospitalization, and the feeding occurred “pleasurably.”

In the single Brazilian case study¹⁷, quality of life was assessed using the Eating Assessment Tool (EAT-10), which includes an impact on swallowing-related life. The score obtained was 15 points, exceeding the cutoff point of 2 points. However, the study did not evaluate the association between dysphagia and quality of life. This was also cited as a criterion used by the multidisciplinary team - “(...) the passage of a nasogastric tube would be a very invasive procedure and would not bring benefits to their quality of life at that moment (...)”, by the patient himself and his mother to choose conduct. In the study on the last 72 hours of life for 164 non-sedated individuals living in the Netherlands¹³, the nursing team and family members attributed average scores of 4.5 and 4.9, respectively, on a scale of 0 to 10, for psychosocial well-being. For physical well-being, the scores were 2.7 and 2.5, with no statistically significant differences.

There was a correlation between loss of appetite and physical well-being, and between swallowing problems, psychosocial and physical well-being, according to the nursing team’s assessment. This latter correlation was also found in the assessment of family members.

In the Italian study¹⁴, swallowing difficulties spontaneously emerged in the discourse of over 80% of interviewed patients and family members regarding challenges in their experience – a concept coherent with that of quality of life. Choking on food or liquids, saliva aspiration, and nutritional issues were reported in 96% of the interviews. Nine patients were receiving nutrition and hydration through gastrostomy. Swallowing difficulties had a significantly negative impact on caregivers, forcing them to spend extended time with the patient and alter their food preparation habits. Aspiration episodes often led to aspirative pneumonia and subsequent hospitalization. There was no information on the awareness of the need for palliative care in patients with dysphagia. Psychological problems were found in many patients and were a source of distress for them and their caregivers/family members. Specifically, patients experienced a sense of abandonment, partly due to their own difficulty in seeking help, lack of sensitivity from others, and the perceived loss of interest from healthcare professionals. These feelings appeared to be related to the patients’ diseases and symptoms, highlighting the need for emotional and psychological support. Many of these patients report feelings of shame, a sense of incapacity, anxiety, and depression due to the loss of independence and consequently, the need for assistance. In social aspects, they reported social isolation, financial difficulties, and stress on family caregivers. Regarding spiritual matters, some patients found hope and support through spiritual/religious guidance, while others showed no interest in these issues. They express anger, a lack of control, and a need for spiritual support. Professionals demonstrated an understanding of the burden on caregivers in physical, psychological, social, and spiritual aspects, as well as their inability to meet the needs of patients. They also confirmed difficulties in determining the number of people in advanced disease stages who might require specialized palliative care and their inability to continue caring for them in their clinics during these disease stages.





We list as relevant considerations from the studies the information that family members and professionals¹³ understood the need for more information from speech therapists or specialists regarding the care and management of swallowing problems in individuals with advanced diseases. Another study¹⁵ suggests that there is a need for more training for specialized speech-language pathologists on the care and management of swallowing problems at the end of life. It is emphasized that the high percentage of dysphagia at the end of life highlights the importance of intervention at this moment. Furthermore, specifically at the end of life, the impact of any interventions for these problems on the quality of life is minimal. Therefore, any proposed intervention should be proportionate to the level of suffering caused by the intervention¹³. The discussion emphasizes that healthcare professionals, including speech-language pathologist, should approach therapeutic decisions with a fresh perspective, starting from the process of shared decision-making and informed choice. In palliative care, the concept of quality of life, a topic widely discussed, can be enhanced by involving the desires of patients and their families in choosing the path to be followed¹⁷. Emphasizing the importance of understanding patients' desires regarding their diet and the meaning they attribute to it, speech-language pathology practice can genuinely contribute to the individual's quality of life¹⁶. In the study on patients with ALS, the need to consider manifestations in a multidimensional way to seek enjoyable eating and quality of life under the principles of palliative care was emphasized, with positive repercussions throughout the progress of the disease¹⁵.

As a limitation, it is acknowledged that this is not a systematic literature review and, therefore, it has a lower level of evidence regarding the direction of conducts.

Considering that we did not find another study like this, it has the potential to contribute reflections to speech-language pathology practice and other professionals involved in the care of adults and elderly individuals with non-oncological diseases requiring palliative care. It may also inspire future studies and public policies.

Final Considerations

This study discussed the literature on the quality of life of adults and elderly individuals living with non-oncological diseases and oropharyngeal dysphagia, requiring predominantly or exclusively palliative care, fostering relevant reflections for clinical practices thereafter.

The literature reviewed proved to be scarce, with diverse methods and small samples, yet consensual regarding the relationship between dysphagia and quality of life. One of them even suggested a positive impact of speech-language pathology intervention on the satisfaction of hospitalized patients regarding their feeding.

These results show a clear need for palliative speech therapy care, considering the quality of life as a measure of the effects of its intervention. Furthermore, there is a need for more studies with a more robust methodology to establish clinical guidelines in palliative speech-language pathology.

References

1. World Health Organization. Global Atlas of Palliative Care at the End of Life. [s.l.]: World Health Organization. 2020. [acesso em 2023 Nov 3]. Disponível em: [https://cdn.who.int/media/docs/default-source/integrated-health-services-\(ihs\)/csy/palliative-care/whpca_global_atlas_p5_digital_final.pdf?sfvrsn=1b54423a_3](https://cdn.who.int/media/docs/default-source/integrated-health-services-(ihs)/csy/palliative-care/whpca_global_atlas_p5_digital_final.pdf?sfvrsn=1b54423a_3)
2. Sleeman KE, Brito M, Etkind S, Nkhoma K, Guo P, Higginson I et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups and health conditions, Lancet Glob Health. 2019; 7(7): e883-e892. doi: 10.1016/S2214-109X(19)30172-X
3. World Health Organization. Palliative care [homepage na Internet]. [s.l.]: World Health Organization. [s.d.]; [acesso em 2023 Nov 3]. Disponível em: <https://www.who.int/health-topics/palliative-care>
4. Kelly K, Cumming S, Corry A, Gilsenan K, Tamone C., Vella K et al. The role of speech-language pathologists in palliative care: Where are we now? A review of the literature. Prog. Palliat. 2016; 24(6): 315-23. doi: 10.1080/09699260.2016.1141745
5. Pascoe A, Breen LJ, Cocks N. What is needed to prepare speech pathologists to work in adult palliative care? Int J Lang Commun Disord. 2018; 53(3): 542-49. doi: 10.1111/1460-6984.12367
6. Sociedade Brasileira de Fonoaudiologia. Respostas para Perguntas Frequentes na Área de Disfagia. [Acesso em 03 Nov 2023]. Disponível em: https://www.sbfa.org.br/portal2017/departamentos/2_disfagia





7. Palecek EJ, Teno JM, Casarett DJ, Hanson LC, Rhodes RL, Mitchell SL. Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr Soc.* 2010; 58(3): 580–4. <https://doi.org/10.1111/j.1532-5415.2010.02740.x>
8. Tan LLC, Lim Y, Ho P, Lim LY, Lim YY, Low JA. Understanding Quality of Life for Palliative Patients With Dysphagia Using the Swallowing Quality of Life (SWAL-QOL) Questionnaire. *Am J Hosp Palliat Care.* 2021; 38(10): 1172-6. <https://doi.org/10.1177/10499091211992532>
9. Organización Mundial de la Salud (OMS). Promoción de la salud: glosario. Ginebra: OMS, 1998. [acesso em 2023 Nov 3]. Disponível em: http://apps.who.int/iris/bitstream/handle/10665/67246/WHO_HPR_HEP_98.1_spa.pdf;jsessionid=A2862BE9A8EC818DACA76AA6CC148459?sequence=1
10. Rivelsrud MC, Hartelius L, Bergström L, Løvstad M, Speyer R. Prevalence of Oropharyngeal Dysphagia in Adults in Different Healthcare Settings: A Systematic Review and Meta-analyses. *Dysphagia.* 2023; 8(1): 76-121. <https://doi.org/10.1007/s00455-022-10465-x>
11. Davis MP, Hui D. Quality of Life in Palliative Care. *Expert Rev Qual Life Cancer Care.* 2017; 2(6): 293-302. <https://doi.org/10.1080/23809000.2017.1400911>
12. Calman KC. Quality of life in cancer patients--an hypothesis. *J Med Ethics.* 1984; 10(3): 124-7. doi: 10.1136/jme.10.3.124
13. Bogaardt H, Veerbeek L, Kelly K, van der Heide A, van Zuylen L, Speyer R. Swallowing problems at the end of the palliative phase: incidence and severity in 164 unselected patients. *Dysphagia.* 2015; 30(2):145-51. doi: 10.1007/s00455-014-9590-1
14. Veronese S, Gallo G, Valle A, Cugno C, Chiò A, Calvo A, Oliver DJ. The palliative care needs of people severely affected by neurodegenerative disorders: A qualitative study. *Prog Palliat Care.* 2015; 23(6): 331–42. doi: 10.1179/1743291X15Y.0000000007
15. Luchesi KF, Silveira IC. Palliative care, amyotrophic lateral sclerosis, and swallowing: a case study. *CoDAS.* 2018; 30(5): e20170215. doi: 10.1590/2317-1782/20182017215
16. Santos LB dos, Mituuti CT, Luchesi KF. Atendimento fonoaudiológico para pacientes em cuidados paliativos com disfagia orofaríngea. *Audiol., Commun. Res.* 2020; 25: e2262. Disponível em: <https://doi.org/10.1590/2317-6431-2019-2262>
17. Jacinto-Scudeiro LA, Ayres A, Olchik MR. Tomada de decisão: papel do fonoaudiólogo em cuidados paliativos. *Distúrb. comun.* 2019; 31(1): 141–6. Disponível em: <https://doi.org/10.23925/2176-2724.2019v31i1p141-146>
18. Portas JG. Validação para a língua português-brasileira dos questionários qualidade de vida em disfagia (SWAL-QOL) e satisfação do paciente e qualidade do cuidado no tratamento da disfagia (AWAL-CARE). [Dissertação]. São Paulo (SP): Fundação Antônio Prudente; 2009. Disponível em: <https://accamargo.phlnet.com.br/MESTRADO/2009/us239.pdf>
19. Gonçalves MIR, Remaili CB, Behlau M. Equivalência cultural da versão brasileira do Eating Assessment Tool - EAT-10. *CoDAS.* 2013; 25(6): 601-4. doi: 10.1590/S2317-17822013.05000012
20. Gapstur RL. Symptom burden: a concept analysis and implications for oncology nurses. *Review Oncol Nurs Forum.* 2007; 34(3): 673-80. doi:10.1188/07.onf.673-680
21. See D, Le B, Gorelik A, Eastman P. Symptom burden in malignant and non-malignant disease on admission to a palliative care unit. *BMJ Support Palliat Care.* 2022; 12(e6): e792-7. doi: 10.1136/bmjspcare-2018-001560
22. CJ Correr, R Pontarolo, AC Melchioris, P Rossignoli, F Fernández-Llimós, RB Radominski. Tradução para o português e validação do instrumento Diabetes Quality of Life Measure (DQOL-Brasil). *Arq Bras Endocrinol Metabol.* 2008; 52: 515-22. Disponível em: <https://doi.org/10.1590/S0004-27302008000300012>
23. Brasil. Ministério da Saúde. Secretaria de Ciência, Tecnologia e Insumos Estratégicos. Departamento de Ciência e Tecnologia. Diretrizes metodológicas: elaboração de revisão sistemática e metanálise de ensaios clínicos randomizados. Brasília: Editora do Ministério da Saúde, 2012. [acesso em 2023 Nov 3]. Disponível em: https://bvsm.sau.gov.br/bvs/publicacoes/diretrizes_metodologicas_elaboracao_sistematica.pdf
24. See D, Le B, Gorelik A, Eastman P. Symptom burden in malignant and non-malignant disease on admission to a palliative care unit. *BMJ Support Palliat Care.* 2022; 12(e6): e792-7. doi: 10.1136/bmjspcare-2018-001560



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