Dysphagia and Quality of Life, Participation, and Inclusion Experiences and Outcomes for Adults and Children with Dysphagia: A Scoping Review

Ms Rebecca Smith (BSpPath (Hons)) [1], Dr Lucy Bryant (PhD) [1], and Prof Bronwyn Hemsley (PhD) [1, 2]

[1] Graduate School of Health, The University of Technology Sydney, Sydney, NSW, Australia, [2] Faculty of Arts and Education, The University of Newcastle, Callaghan, NSW, Australia

Author Note

Rebecca Smith ORCID ID: 0000-0001-9523-785X

Lucy Bryant ORCID ID: 0000-0001-8497-7406

Bronwyn Hemsley ORCID ID: 0000-0002-6255-3140

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Correspondence concerning this article should be addressed to Rebecca Smith, Graduate School of Health, the University of Technology Sydney, 100 Broadway, Ultimo, NSW, Australia, 2007. Email: rebecca.j.smith@student.uts.edu.au. Phone: +61 2 9514 2000

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Abstract

Purpose. Research shows that dysphagia impacts quality of life negatively, but the nature of these impacts is not well understood. This review aims to examine the impacts of dysphagia and its interventions on mealtime-related quality of life, participation, and inclusion for people with dysphagia.

Methods. The protocol for this scoping review was published in July 2019 and involved a search of five scientific databases using dysphagia and quality of life related terms.

Results. In total, 106 studies were included in the review. A qualitative metasynthesis demonstrated that dysphagia had various negative impacts on quality of life, particularly in populations with severe dysphagia. Dysphagia interventions had a range of positive impacts on quality of life, however modifying food texture also had negative impacts. Most studies (*n*=95) included adults with acquired dysphagia. Only seven included people with lifelong conditions including cerebral palsy or intellectual disability; and only four included children. Almost half of the studies (*n*=44) used quantitative instruments, including the Swallowing Quality of Life Questionnaire or the Eating Assessment Tool (EAT-10), to measure the impact of dysphagia on quality of life and few used qualitative approaches.

Conclusions. There are both positive and negative impacts of dysphagia and dysphagia-related interventions on quality of life, participation, and inclusion. Most research is quantitative and limited to adults with acquired dysphagia. Qualitative and longitudinal studies that include populations with lifelong disability and children are needed to determine how dysphagia and its interventions impact on quality of life across conditions and over the lifespan.

Keywords: Dysphagia, quality of life, scoping literature review.

Introduction

Dysphagia and its Interventions: Quality of Life Impacts

Dysphagia (difficulty swallowing) is highly prevalent, estimated to affect approximately 8% of the world's population (Cichero et al., 2017). Dysphagia is associated with a wide range of lifelong conditions (e.g., cerebral palsy, intellectual disability, Down syndrome, and autism) (Sheppard et al., 2014) and acquired conditions (e.g., cerebrovascular accident (CVA), traumatic brain injury, dementia, Parkinson's disease, multiple sclerosis, motor neurone disease (MND) or amyotrophic lateral sclerosis (ALS), and head and neck cancer) (Groher & Crary, 2016). The prevalence of dysphagia varies widely across conditions. For example, it is estimated that dysphagia affects as many as 45.06% of people with stroke (Rofes et al., 2018) and 85% of children with cerebral palsy (Benfer et al., 2013). Older people also have an increased risk for swallowing difficulties; an estimated 40-60% of older people in nursing homes have dysphagia (Eisenstadt, 2010; Shanley & O'Loughlin, 2000). Dysphagia broadly impacts on health and wellbeing, as health is defined as a position of total wellbeing related to physical, psychological, and social health (World Health Organization, 1946, 2001). Dysphagia can cause multiple psychosocial and physical impacts, including reduced quality of life, poor respiratory or nutritional health, and premature death from choking or aspiration pneumonia (Hemsley, Steel, et al., 2019).

Food or fluid texture modification, one of the main compensatory interventions for dysphagia (United Kingdom National Health Service, 2021), aims to sustain or increase oral food intake and nutrition while maintaining the person's respiratory health (Groher & Crary, 2016; Wu et al., 2020). The need for texture-modified food is based on clinical and instrumental swallowing assessments; with food textures commonly classed according to the International Dysphagia Diet Standardization Initiative categories of Regular/Easy to Chew (Level 7), Soft and Bite-Sized (Level 6), Minced and Moist (Level 5), Pureed (Level 4), or Liquidized (Level 3) (Cichero et al., 2017). Fluid textures are further classified as Extremely Thick (Level 4), Moderately Thick (Level 3), Mildly Thick (Level 2), Slightly Thick (level 1), and Thin (Level 0). Extensive evidence supports the view that appropriately modified food and fluid increases a person's physical health and safety through reduced aspiration or choking risk (see Steele et al., 2015). However, texture modification may also cause health-related complications. For example, decreased fluid intake may occur if the person dislikes thickened fluids (Swan et al., 2015). This can have severe consequences on the person's physical health, including kidney dysfunction and delirium for medically unwell people (Swan et al., 2015). In addition, thickening of fluids increases viscosity and reduces flow rate during the swallow but can cause adverse effects including pooling of fluids in the mouth or the vallecular space (Johnson et al., 2014). Although texture modification ensures that food is the correct consistency, it can change the food's temperature or taste, thus reducing the person's mealtime enjoyment (Reissig, 2017).

Thus, it is apparent that dysphagia and a texture-modified diet can negatively impact a person's quality of life, particularly as the severity of dysphagia increases (Jones et al., 2018). The World Health Organization defines quality of life as a person's awareness and judgement of their position in life regarding cultural beliefs and values, and concerns (World Health Organization, 1998). Quality of life is a broad concept that incorporates physical and mental health, beliefs, personal relationships, and the environment (World Health Organization, 1998). Mealtime participation considers how a person engages in mealtime-related activities (e.g., choosing foods, or food preparation), and extends to social or workplace situations and cultural events (Balandin et al., 2009).

In this review, the Health-Related Quality of Life Model (HRQOL) was used to conceptualize mealtime-related quality of life, which is quality of life driven by events surrounding mealtimes (Ferrans et al., 2005). HRQOL refers to the impact of a person's health on quality of life (Karimi & Brazier, 2016). As such, the HRQOL model demonstrates the impacts of the health condition and its treatments on quality of life (Ferrans et al., 2005). HRQOL is affected by a person's swallowing function, dysphagia symptoms, treatments, and general health, as well as personal and environmental characteristics. Thus, both dysphagia symptoms and treatments could positively or negatively impact on quality of life (Ferrans et al., 2005). An improved understanding of how dysphagia and its interventions might affect a person's mealtime quality of life, participation, and inclusion, could guide policy and practice to improve or maintain health-related quality of life in people with dysphagia. Dodrill and Estrem (2019) also related the outcomes of swallowing difficulties in children to HRQOL and reported that children with dysphagia face many of the same difficulties faced by adults with dysphagia. Negative outcomes may be driven by fatigue from eating, reduced enjoyment of meals, or reduced participation in events due to the compensatory strategies required (Dodrill & Estrem., 2019).

Reviewing the evidence from different populations with dysphagia could provide important insights into balancing the impact of dysphagia and its interventions on both health and quality of life. In a recent review of choking, both a symptom and a sequela of dysphagia, Hemsley, Steel, et al. (2019) outlined the value of considering evidence across populations and identified common risk factors and management strategies to reduce the choking risk for people with or without dysphagia. Examining studies about swallowing-related quality of life across populations may provide further insights into the impacts of dysphagia and of its interventions, and yield important insights and comparisons to guide overarching policies and practices. Examining literature across populations necessarily increases the requirement to expand the inclusion criteria to ensure consideration for smaller and more diverse populations. In systematically reviewing the impact of oropharyngeal dysphagia on a person's quality of life, Jones et al. (2018) excluded studies with less than 15 participants, potentially excluding important smaller scale in-depth qualitative research, on highly heterogeneous populations (e.g., people with lifelong disability) which could provide important insights into the lived experience of dysphagia and impacts on quality of life through in-depth qualitative analysis. Furthermore, many of the articles included in Jones et al. (2018) focus on people with acquired rather than lifelong developmental conditions. Therefore, the aim of this review was to conduct a scoping review of research on the impacts of dysphagia *and* its interventions on quality of life, participation, and inclusion for children and adults across populations with either lifelong developmental dysphagia or acquired dysphagia.

Methods

The review protocol was registered with PROSPERO (Smith et al., 2019). In July 2019, five scientific databases were searched by the first author. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009) was followed and an adapted PRISMA statement established. The PRISMA extension for Scoping Reviews (PRISMA-ScR) checklist was also implemented as part of this scoping review (Tricco et al., 2018). No time limitations for publication year were imposed. Boolean phrases "OR", and "AND" combined the search terms (see Supplementary Materials, S1).

Inclusion and Exclusion Criteria

This review included papers that were: (1) peer reviewed full papers in English outlining original research, and (2) related to dysphagia *and* its impact on quality of life, participation, or inclusion. Original research, including qualitative, quantitative, and mixed-methods studies or systematic reviews relating to children over two years of age and adults, were included. Any study that did not meet the above criteria were excluded. Furthermore, the authors of this review made a consensus decision to exclude 13 studies relating to patients with head and neck cancer, whose primary interventions were for cancer and not dysphagia, and whose quality of life impacts were primarily related to the impacts of cancer treatment. As the studies using Eating Assessment Tool (EAT-10) in this review had used the tool specifically to measure quality of life, not only symptom outcomes, a consensus decision was made by the authors of this review to include studies using symptoms measures such as the EAT-10 (Belafsky et al., 2008). It was considered that studies using EAT-10 as a measure of quality of life could yield important information on how researchers to date have defined and measured quality of life in relation to dysphagia.

References were imported into EndNote (Clarivate Analytics, 2019) before applying the inclusion or exclusion criteria. The first author screened titles and abstracts and the second author checked all decisions. The remaining full texts were then rated by the first and third authors, reaching a consensus decision on inclusion. A third rater (the second author) was brought in to make a decision if consensus could not be reached between the two raters. Ancestry searches and forward citations of the included studies were retrieved for consideration against the inclusion criteria using the same method to arrive at the final list of included studies.

Quality Assessment

The Quality Assessment Tool for Studies with Diverse Design (QATSDD) (Sirriyeh et al., 2012) was used to assess the quality and potential bias of the included studies. The QATSDD is a 16-item quality assessment tool used to evaluate quantitative, qualitative, and mixed-methods research designs (Sirriyeh et al., 2012). Reasonable sample size judgements were based on findings of Peduzzi et al. (1996) who discussed that at least 10 participants are required per variable, or a sample size of 150 participants is needed. In the QATSDD, qualitative and quantitative studies are scored from zero to three on 14 items (maximum score of 42), and mixed-methods studies are scored on 16 items (maximum score of 48) (Sirriyeh et al., 2012). This assessment was completed separately by the first and second authors. Where consensus was not reached, the third author assisted to reach a majority decision.

Data Analysis

Data extracted from the studies included the type of study, number of participants, and relevant results on the relationship between dysphagia, and quality of life, inclusion, and participation. An integrative review method (Whittemore & Knafl, 2005) allowed for relevant results from all study types to be combined and analysed in a qualitative metasynthesis. Extracted data was read and re-read by the authors and converted into units of meaning, discussed, and formed into categories using NVivo (QSR International, 2018). In the metasynthesis, data was analysed across studies to identify themes and sub-themes. Data was also examined to identify common and unusual patterns, determine relationships and to make contrasts and comparisons between the categories of meaning (Whittemore & Knafl, 2005).

Results

Characteristics of the Included Studies

The initial search identified 15,448 articles, 80 of which met the inclusion criteria. Ancestry searches and forward citations checks allocated a further 26 studies, resulting in a total of 106 studies being included in this review, see the full list of studies (Supplementary Materials S3 andS4) and the PRISMA statement (Supplementary Materials S2). The inter-rater reliability of decisions during full text review was 87%, demonstrating high agreement (McHugh, 2012).

The average QATSDD score was 73%, with a minimum of 50% (Aruga et al., 2018; Farri et al., 2007) and a maximum of 93% (Kim et al., 2005). Reflecting on the inclusion of smaller-scale qualitative studies, two reports had a single case study design (Malandraki et al., 2014; Sanchez-Kuhn et al., 2019), and 14 had 2-10 participants (Aruga et al., 2018; Athukorala et al., 2014; Ayres et al., 2016; Carlsson et al., 2004; Frost et al., 2018; Hellden et al., 2018; Johansson & Johansson, 2009; Klinke et al., 2014; LaDonna et al., 2016; Luchesi & Silveira, 2018; Malandraki et al., 2016; Martino et al., 2010; Moloney & Walshe, 2018; Remijn et al., 2019). Reporting of recruitment was relatively poor: 22 studies provided either no or minimal recruitment data, scoring 0 or 1 on the QATSDD rating for that item. Furthermore, only five studies explicitly described stakeholder involvement in the study design with clients or steering groups (Ang et al., 2019; Carlozzi et al., 2016; Diniz et al., 2018; Karagiannis & Karagiannis, 2014; Remijn et al., 2019) indicating there was little input from people with dysphagia in research to date on dysphagia-related quality of life (see Supplementary Materials, S3 for overall QATSSD scores). Almost all of the included studies (*n* = 95; 93%) related to dysphagia in populations with acquired conditions. Only seven of the 106 studies (7%) related to populations with dysphagia associated with lifelong developmental health conditions.

Systematic Reviews Included in this Review

Eight reviews examined the impacts of dysphagia and dysphagia-related interventions on quality of life for populations with specific health conditions (Carneiro et al., 2013; Katzberg & Benatar, 2011; Klinke et al., 2013; Langmore et al., 2006; Li & Deng, 2019), or focused on people with oropharyngeal dysphagia (Jones et al., 2018; Swan et al., 2015; Verdonschot et al., 2017). The impacts of percutaneous endoscopic gastrostomy (PEG) feeding for people with MND/ALS were examined in two reviews (Katzberg & Benatar, 2011; Langmore et al., 2006). Similarly, Carneiro et al. (2013) focused on dysphagia-related quality of life impacts for people with Parkinson's, while Li and Deng (2019) and Klinke et al. (2013) focused on people with dysphagia after a CVA. None of the included reviews provided a holistic view of the impacts of lifelong or acquired dysphagia and their interventions on the individual. Details of prior systematic reviews are presented in the Supplementary Materials, S4.

Studies Examining the Impacts of Dysphagia on Adults

Overall, 63 (61%) original studies examined the impacts of dysphagia on the quality of life, participation, and inclusion of adults. There were 40 quantitative, 17 qualitative, and six mixed-methods studies, representing various populations with dysphagia (see Supplementary Materials, S3). Table 1 details the impacts of dysphagia on participants and relates these to the HRQOL model. All included studies found that dysphagia impacted negatively on participants' quality of life, particularly reducing their emotional and biopsychosocial wellbeing. Furthermore, greater severity of dysphagia significantly correlated with reductions in quality of life (Arslan et al., 2019; Carneiro et al., 2014; Da Costa Franceschini & Mourao, 2015; Hong & Yoo, 2017; Luchesi & Silveira, 2018; Pierce et al., 2016; Song et al., 2020; Turley & Cohen, 2009; Vogel et al., 2014). However, duration of dysphagia did not always make a difference, in six studies where dysphagia symptoms were stable, there was no correlation between the duration of dysphagia and quality of life impacts (Carneiro et al., 2014; Kim et al., 2005; Leow et al., 2010; Plowman-Prine et al., 2009; Pontes et al., 2017; van Hooren et al., 2016) (see Table 1).

Insert Table 1 about here.

Measurement of quality of life. In total, 20 quantitative assessment tools were used in the studies to measure quality of life (see Supplementary Materials, S5). Three of the studies outlined the development of the Swallowing Quality of Life Questionnaire (SWAL-QOL) (McHorney, Bricker, Kramer, et al., 2000; McHorney, Bricker, Robbins, et al., 2000; McHorney et al., 2002). McHorney, Bricker, Kramer, et al. (2000) conducted focus groups with people with dysphagia to develop a conceptual foundation and established the SWAL-QOL and Quality of Care in Swallowing Disorders Surveys (McHorney, Bricker, Robbins, et al., 2000). The SWAL-QOL was then validated with participants with and without dysphagia, and results showed significant differences in scores between groups highlighting the impact of dysphagia on quality of life (McHorney et al., 2002).

Overall, the SWAL-QOL and/or the EAT-10 were used in 44 of the studies. In studies using the SWAL-QOL, participants with dysphagia had significantly reduced quality of life across all domains (McHorney et al., 2002); burden, food selection, frequency of symptoms, eating, fear, fatigue, sleep, communication, mental health, social role, information, and quality of services (Carneiro et al., 2014; Diniz et al., 2018; Vogel et al., 2017).

Another four studies used condition-specific assessments, including assessments specific to Huntington’s disease or Parkinson’s (Carlozzi et al., 2016; Plowman-Prine et al., 2009). Other assessment items that were used less frequently included the Communication Participation Item Bank (McAuliffe et al., 2017) and the M.D. Anderson Dysphagia Inventory (Chen et al., 2009; Roy et al., 2007; Roy et al., 2018). One study conducted multiple regression analysis to account for the impact of dysphagia on quality of life and other independent variables (Morisaki, 2017). The authors reported that mental health, activities of daily living, and general health significantly differed in community dwelling elderly people with dysphagia and these factors were associated with their quality of life (Morisaki, 2017). Across all of the included studies, quantitative measures provided little in-depth exploration of the experience of dysphagia or dysphagia-related interventions on quality of life, participation, or inclusion.

Qualitative and mixed methods studies examining quality of life and dysphagia. The mixed-methods and qualitative studies included in this review made up just over one third of the original research, and utilized interviews (*n* = 22), observations (*n* = 3), focus groups *(n* = 2), open-ended questionnaires *(n* = 2), and autobiographies (*n* = 1) (see Supplementary Materials, S3).

Content themes in the qualitative elements of the studies are presented in Table 1 with illustrative quotes in Table 2.

Participants described emotional responses to dysphagia and its interventions, including frustration, humiliation, loss, and fear of choking. Miller et al. (2006) described participants' feelings of "guilt and selfishness" (p. 616) as family mealtimes were no longer enjoyable for people with dysphagia. Nyberg et al. (2018) also reported that participants believed their mealtimes were "not performed in a culturally proper way" (p. 93) and they tried to maintain normality and inclusion by choosing regular foods that they could eat. LaDonna et al. (2016) described similar coping strategies to overcome isolation, for example, by choosing meals that the person with dysphagia could share with friends and family (see further examples in Table 2). Some people with dysphagia described pretending to drink coffee in front of others to maintain the appearance of normality and "proper" mealtime cultural norms (Klinke et al., 2014). Moloney and Walshe (2018) examined the autobiographies of 10 people with dysphagia secondary to CVA and reported that dysphagia had significant emotional and social impacts for participants (Moloney & Walshe, 2018).

Insert Table 2 about here.

Across the studies, various psychosocial and mental health impacts were associated with dysphagia, including symptoms of depression or anxiety (Eslick & Talley, 2008; Tibbling & Gustafsson, 1991; Verdonschot et al., 2013; Verdonschot et al., 2017). Verdonschot et al. (2016) found that the relationship between anxiety, "piecemeal deglutition" (p. E202) and the post-swallow vallecular pooling of thickened liquids was significant, as was the relationship between depressive symptoms and dysphagia. However, Verdonschot et al. (2016) also found that the probability of having anxiety decreased as dysphagia severity increased, suggesting that this was because people with more severe dysphagia had a longer disease history, no longer causing them increased anxiety (Verdonschot et al., 2016).

The Impact of Dysphagia Interventions on Quality of Life in Adults with Dysphagia

In total, 32 (30%) of the included studies examined the impacts of dysphagia interventions on quality of life for adults (see Supplementary Materials, S3). Of these, the majority (*n* = 25) reported that a wide variety of dysphagia interventions positively impacted on quality of life (see Table 1). However, there was much variation between studies regarding study design - with samples ranging from 1-124 participants (Unluer et al., 2019; Xia et al., 2016), and variation in therapy intensity which reduced confidence in the findings. Two studies revealed that enteral tube feeding had positive and negative impacts on quality of life (Ang et al., 2019; Stavroulakis et al., 2016). Another study reported the negative impacts of texture-modified foods (Seshadri et al., 2018), however, dysphagia severity or progression of the associated health condition may have influenced the outcome. In four studies there was no significant difference in quality of life after therapy (Hagglund et al., 2019; Kelly et al., 2013; Reyes et al., 2015; Sundstedt et al., 2016). Dysphagia interventions also impacted on the person's inclusion and participation (e.g., Ang et al., 2019; Seshadri et al., 2018; Stavroulakis et al., 2016; Unluer et al., 2019). Stavroulakis et al. (2016) and Ang et al. (2019) reported that gastrostomy feeding was isolating for people as they could not share communal meals, while Seshadri et al. (2018) reported that texture-modified diets similarly caused isolation from social gatherings. Unluer et al. (2019) then found that repetitive transcranial magnetic stimulation used in conjunction with traditional swallowing intervention had greater impacts on social functioning than traditional swallowing therapy alone.

In four of the studies examining the impacts of dysphagia on quality of life in adults, both dysphagia symptoms and texture-modified diets commonly impacted on quality of life (Hellden et al., 2018; Milte et al., 2017; Moloney & Walshe, 2018; Shune & Linville, 2019). Shune and Linville (2019) highlighted that it was not just swallowing difficulties that led to a person's reduced participation and a sense of exclusion, but also the appearance of the texture-modified food. They reported that texture-modified food made people feel "self-conscious or like, 'Why me? Why do I have to eat this?'" (Shune & Linville, 2019, p. 149). Similarly, Hellden et al. (2018) reported that texture-modified diets made it challenging to eat away from home as it was difficult to find foods of an appropriate texture. Milte et al. (2017) reported that participants weighed up food safety of a meal (i.e., would it increase dysphagia symptoms or did it meet diet recommendations) with the expected enjoyment of the meal when making food choices. This highlighted the impact of food choices on quality of life for people with dysphagia who require texture modified food.

Studies Examining the Impacts of Dysphagia on Children

Only four studies included children aged over two years in their sample, highlighting the limited focus of research on children. Dysphagia led to higher anxiety, lower self-esteem, and negative impacts on social participation for children (Gustafsson & Theorell, 1995). Regarding intervention, Mahant et al. (2011) reported that enteral tube feeding negatively impacted on the quality of life for children and their families. In comparison, Malandraki et al. (2014) reported that intensive swallowing telepractice therapy improved EAT-10 scores, indicating that therapy did result in improvements to quality of life.

Discussion

The findings of prior research examining the views and experiences of people with dysphagia are of vital importance for informing interventions that improve their quality of life. In this review, valuable insights into the lived experience of people with dysphagia reveal the extra effort required for them to be included in mealtime-related activities and underline the significance of mealtime-related participation and inclusion for this group. Nonetheless, the findings of this review indicate that despite there being several systematic reviews and individual studies examining quality of life impacts of dysphagia and its intervention, few studies yield an in-depth understanding of mealtime-related quality of life or mealtime participation and inclusion for people with dysphagia. Most studies used quantitative instruments (e.g., the SWAL-QOL or EAT-10), providing only glimpses into the lived experiences of people with dysphagia from their own perspective or the perspective of their supporters. Furthermore, few studies reported any stakeholder involvement in the study design.

Over-reliance on Quantitative Measures and Cross-Sectional Designs

In the studies identified in this review, the frequent use of the SWAL-QOL (McHorney, Bricker, Kramer, et al., 2000; McHorney, Bricker, Robbins, et al., 2000; McHorney et al., 2002), often the sole means of measuring quality of life in these studies, indicates an over-reliance on quantitative methods to explore what is essentially a qualitative, human experience. To date, there has been an under-utilization of rigorous qualitative research methods which would provide important insights into the nature of dysphagia, its interventions, and mealtime experiences. Similarly, common use of the EAT-10 (which is not a quality of life measure) to assess mealtime-related quality of life could indicate the absence of more suitable tools and a need for further tool development in this area. Furthermore, our quality appraisal of studies revealed high variability in their quality. Nonetheless, studies with smaller samples provided useful insights into the quality of life impacts of dysphagia and its interventions that should inform training for those who provide mealtime assistance to people with dysphagia.

There was a reliance on cross-sectional designs and there were no longitudinal studies that examined dysphagia-related quality of life across the lifespan. Such research would allow for the adaptation and development of strategies to increase the participation and inclusion of people with dysphagia on texture-modified diets (e.g., through greater community knowledge of dysphagia, and the availability of texture-modified foods in cafes and restaurants). Given the impact of the problematic appearance of puree foods on mealtime enjoyment, further solutions to increase the appeal of texture-modified foods may require technical advancements to make attractive texture-modified foods more widely available (Hemsley, Palmer, et al., 2019).

Clinical Implications

The findings of this review reveal significant gaps in the literature on the quality of life impacts of dysphagia and its interventions for people with lifelong (developmental) disability. The experiences and impacts of dysphagia on quality of life may differ widely for people with lifelong dysphagia when compared to those reported by people with acquired dysphagia. Their lived experiences of dysphagia and its interventions over a lifetime might provide important insights into the impacts of chronic dysphagia. For example, individuals with cerebral palsy or intellectual disability could provide insights into the impact of mealtime assistance, managing texture-modified foods across the lifespan, and accessing supports to improve mealtime participation and inclusion (Benfer et al., 2015). People with developmental disability may also experience a decline in swallowing function after the third decade of life (Balandin et al., 2009). Their views on dysphagia-related quality of life are likely to be quite different to adults with progressive symptoms associated with acquired conditions including MND (Stavroulakis et al., 2016) and Parkinson's (Carneiro et al., 2014). In comparison, adults with acquired dysphagia secondary to a CVA, experience a sudden loss of function, enjoyment, and independence, requiring significant adjustments owing to mealtime assistance or texture-modified foods not previously needed. This may limit their mealtime enjoyment through loss and grief (Hong & Yoo, 2017).

Overall, this review suggests that dysphagia-related quality of life is under-researched in children with dysphagia, leaving clinicians without detailed evidence-based guidance on management for this group. Examining the experiences of children with dysphagia could identify aspects of dysphagia that should be measured across the lifespan to determine the lifetime impacts on quality of life. The need for texture-modified foods from childhood is likely to shape personal factors including attitudes, knowledge, beliefs towards foods, and potentially development of understanding of balancing the risks and benefits of various food choices. Further research should examine how family members, health professionals, and peers, support children with dysphagia in shaping these personal responses to dysphagia and its interventions. This would enable clinicians to support people with lifelong disability and dysphagia along with their families to enhance mealtime-related quality of life, participation, and inclusion across the lifespan.

Considering the high prevalence of dysphagia in children and adult with conditions associated with developmental disability, a greater understanding of quality of life impacts is needed to demonstrate ways to reduce the incidence of preventable choking deaths in this population (Hemsley, Steel, et al., 2019). If the psychosocial costs of maintaining a texture-modified diet (e.g., decreased quality of life) are greater than the perceived benefits (e.g., reduced choking and improved respiratory health and nutrition), people with dysphagia associated with lifelong disability and their families may abandon dietary modifications designed to reduce the health risks. Thus a greater understanding of strategies to improve the quality of life of a person on a texture-modified diet may reduce morbidity and mortality in individuals with lifelong disability.

Limitations and Directions for Future Research

This study was limited by only including studies in English and a publication bias by requiring peer-reviewed articles. Although the literature search was conducted in July 2019, to reduce the impact of this limitation, the search was updated in August 2020 to locate any further studies meeting the inclusion criteria that offered further insights the findings of the review. Overall, 10 additional studies were found which are summarized in Supplementary Materials, S6. Only two of these studies included participants with dysphagia associated with lifelong conditions (Padilla et al., 2019; Pilz et al., 2020) and the remainder included participants with acquired dysphagia (Byeon, 2020; Chan et al., 2020; Covello et al., 2020; Kim et al., 2019; Rönnefarth et al., 2020; Shune & Namasivayam-MacDonald, 2020; Swales et al., 2020; Toledo-Rodríguez et al., 2019). All studies used a quantitative measure of quality of life, with seven using the SWAL-QOL. Two of the studies involving people with acquired dysphagia also used qualitative open-ended surveys or interviews (Padilla et al., 2019; Swales et al., 2020). Thus, studies located from July 2019 to August 2020 aligned with findings of this review and did not change the results.

Future research exploring the theoretical constructs of dysphagia-related quality of life could help to guide the design and development of new quality of life measures that are relevant across populations. It could also inform factors to be measured in controlled trials of interventions aiming to improve quality of life for people with dysphagia. Future research should also include children with lifelong disability who face a life course trajectory of ongoing impacts of both dysphagia and its interventions, and whose experiences could inform planning and preparation for support strategies needed to sustain their quality of life as they get older.

Conclusion

Dysphagia and its interventions can significantly impact a person's quality of life, participation, and inclusion, and as a result, clinicians should take a holistic approach to their assessment and management of dysphagia to promote the person's quality of life. While there is a large body of literature relating to dysphagia-related quality of life across populations with dysphagia, it primarily relates to adults with acquired conditions and uses quantitative assessment measures to understand quality of life impacts. This could leave clinicians working with people with dysphagia uncertain about evidence-based strategies for improving dysphagia-related quality of life. The findings of this review across populations' highlights that dysphagia and its interventions can have a negative impact on a person's quality of life, particularly on psychosocial wellbeing and social isolation. Strategies to provide more enjoyable meals to people who require texture-modified foods are also needed. Future research should include qualitative and longitudinal methods for a rich, in-depth understanding of mealtime-related quality of life across the lifespan for people with dysphagia.

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Description of Supplementary Materials:

S1: S1 is a table outlining the search strategy used for this scoping review in Medline.

S2: S2 is a figure of the adapted PRISMA inclusion figure.

S3: S3 is a table that includes a description of studies included (excluding systematic reviews).

S4: S4 is a table that provides a description of all systematic reviews included in this scoping review.

S5: S5 is a table outlining the quality of life assessment tools used in each study.

S6: S6 is a table of the additional studies found in the search completed in August 2020.

Table 1

Themes Identified Regarding Quality of Life and Their Relationship to the HRQOL Model (Ferrans et al., 2005)

Theme and subthemes	Component of HRQoL model addressed by theme	References
Attempts to maintain quality of life (a) Personal attempts to maintain quality of life (b) Eating regular food	(1)Characteristics of the individual (2) overall quality of life.	(a) (Klinke et al., 2013; Klugman & Ross, 2002; Luchesi & Silveira, 2018; Milte et al., 2017; Moloney & Walshe, 2018; Nyberg et al., 2018; Perry & McLaren, 2003; Pontes et al., 2017; Seshadri et al., 2018; Shune & Linville, 2019; Tarlarini et al., 2019) (b) (Hellden et al., 2018; Johansson & Johansson, 2009; Klinke et al., 2013; LaDonna et al., 2016; Martino et al., 2010; Milte et al., 2017; Moloney & Walshe, 2018; Perry & McLaren, 2003; Seshadri et al., 2018; Shune & Linville, 2019)
Biopsychosocial impacts (a) Fatigue and sleep effects (b) Increased time to eat (c) Negative mental health impacts (d) Reduced desire to eat (e) Associated risk factors to dysphagia	(1)Characteristics of the individual (2) biological function (3) symptoms (4) functional health status (5) general health perceptions.	(a) (Arslan et al., 2019; Balandin et al., 2009; de Faria Gaspar et al., 2015; Gustafsson & Theorell, 1995; Klinke et al., 2013; Medin, Larson, et al., 2010; Medin, Windahl, et al., 2010; Miller et al., 2006; Paris et al., 2013; Printza et al., 2020; Wegner et al., 2018; Yi et al., 2019) (b) (Balandin et al., 2009; de Faria Gaspar et al., 2015; Martino et al., 2010; Printza et al., 2020; Remijn et al., 2019; Song et al., 2019; Wegner et al., 2018; Yi et al., 2019) (c) (Balandin et al., 2009; Carneiro et al., 2013; de Faria Gaspar et al., 2015; Ekberg et al., 2002; Farri et al., 2007; Gustafsson & Theorell, 1995; Hewett et al., 2016; Johansson & Johansson, 2009; Klinke et al., 2013; Klugman & Ross, 2002; Manor et al., 2018; Martino et al., 2010; Moloney & Walshe, 2018; Morisaki, 2017; Pierce et al., 2016; Plowman-Prine et al., 2009; Printza et al., 2020; Roy et al., 2007; Tibbling & Gustafsson, 1991; Turley & Cohen, 2009; Verdonschot et al., 2013; Verdonschot et al., 2016; Verdonschot et al., 2017) (d) (Alali et al., 2018; Balandin et al., 2009; Da Costa Franceschini & Mourao, 2015; Ekberg et al., 2002; Farri et al., 2007; Klinke et al., 2013; Leow et al., 2010; Medin, Larson, et al., 2010; Miller et al., 2006; Moloney & Walshe, 2018; Paris et al., 2013; Pitts et al., 2019; Remijn et al., 2019) (Balandin et al., 2009; Byeon, 2019; Klinke et al., 2013; Leow et al., 2010; McAuliffe et al., 2017; Pierce et al., 2016; Yi et al., 2019)
Emotional response (a) Fear of choking (b) Frustration	(1)Characteristics of the individual (2) biological	(a) (Balandin et al., 2009; Carlsson et al., 2004; Ekberg et al., 2002; Jacobsson et al., 2000; Klinke et al., 2013; Manor et al., 2018; Martino et al., 2010; Medin, Larson, et al., 2010; Moloney & Walshe, 2018)

(c) Humiliation (d) Incompetency (e) Loss	function (3) symptoms (4) functional health status (5) overall quality of life.	(b) (Alali et al., 2018; Balandin et al., 2009; Klinke et al., 2013; Martino et al., 2010; Moloney & Walshe, 2018) (c) (Ang et al., 2019; Balandin et al., 2009; Jacobsson et al., 2000; Klinke et al., 2014; Klinke et al., 2013; Luchesi & Silveira, 2018; Martino et al., 2010; Medin, Larson, et al., 2010; Medin, Windahl, et al., 2010; Moloney & Walshe, 2018; Remijn et al., 2019; Shune & Linville, 2019) (d) (Balandin et al., 2009; Klinke et al., 2013; Perry & McLaren, 2003; Roy et al., 2007) (e) (Balandin et al., 2009; Carlsson et al., 2004; Gustafsson & Theorell, 1995; Jacobsson et al., 2000; Johansson & Johansson, 2009; Klinke et al., 2013; Klugman & Ross, 2002; Luchesi & Silveira, 2018; Martino et al., 2010; Medin, Larson, et al., 2010; Medin, Windahl, et al., 2010; Miller et al., 2006; Moloney & Walshe, 2018; Perry & McLaren, 2003)
Impact on family/ carers (a) Emotional impact on family (b) More support required (c) New role in mealtime support/ responsibility	(1)Characteristics of the environment (2) functional status (3) general health perceptions (4) overall quality of life.	(a) (Balandin et al., 2009; Johansson & Johansson, 2009; Mahant et al., 2011; Miller et al., 2006; Moloney & Walshe, 2018) (b) (Balandin et al., 2009; Mahant et al., 2011; Moloney & Walshe, 2019; Shune & Linville, 2019) (c) (Balandin et al., 2009; Mahant et al., 2011; Malandraki et al., 2014; Miller et al., 2006; Moloney & Walshe, 2018)
Social isolation (a) Avoiding eating in social situations (b) Communication difficulties (c) Loss of independence (d) Reduced participation (e) Saving face around others (f) Treatment by others	(1)Characteristics of the individual (2) characteristics of the environment (3) symptoms (4) functional status (5) overall quality of life.	(a) (Alali et al., 2018; Balandin et al., 2009; Da Costa Franceschini & Mourao, 2015; Diniz et al., 2018; Ekberg et al., 2002; Farri et al., 2007; Hellden et al., 2018; Klinke et al., 2014; Klinke et al., 2013; Martino et al., 2010; Medin, Larson, et al., 2010; Miller et al., 2006; Moloney & Walshe, 2019; Nyberg et al., 2018; Remijn et al., 2019; Roy et al., 2007; Tibbling & Gustafsson, 1991) (b) (Balandin et al., 2009; Klinke et al., 2013; McAuliffe et al., 2017; Yi et al., 2019) (c) (Alali et al., 2018; Balandin et al., 2009; Gustafsson & Theorell, 1995; Jacobsson et al., 2000; Klinke et al., 2013; Mahant et al., 2011; Medin, Windahl, et al., 2010; Moloney & Walshe, 2018) (d) (Ang et al., 2019; Arslan et al., 2019; Carlsson et al., 2004; de Faria Gaspar et al., 2015; Diniz et al., 2018; Mahant et al., 2011; Manor et al., 2018; Medin, Larson, et al., 2010; Milte et al., 2017; Nyberg et al., 2018; Paris et al., 2013; Perry & McLaren, 2003; Plowman-Prine et al., 2009; Remijn et al., 2019; Roy et al., 2007; Shune & Linville, 2019; Stavroulakis et al., 2016) (e) (Ang et al., 2019; Balandin et al., 2009; Hellden et al., 2018; Klinke et al., 2014; Klinke et al., 2013; Klugman & Ross, 2002; Medin, Windahl, et al., 2010; Milte et al., 2017; Perry & McLaren, 2003; Seshadri et al., 2018)

		(f) (Alali et al., 2018; Carlsson et al., 2004; Johansson & Johansson, 2009; Klinke et al., 2013; Mahant et al., 2011; Miller et al., 2006; Moloney & Walshe, 2018; Shune & Linville, 2019)
Measurement of impacts (a) Assessment use and development to measure quality of life (b) Correlation between severity of dysphagia and the impact on quality of life (c) Correlation between time with dysphagia and quality of life (d) Confirmation of the impacts of dysphagia on quality of life	(1)Biological function (2) symptoms (3) functional status (4) general health perceptions (5) overall quality of life.	(a) (Aruga et al., 2018; Carlozzi et al., 2016; Jones et al., 2018) (b) (Arslan et al., 2019; Carneiro et al., 2013; Carneiro et al., 2014; Da Costa Franceschini & Mourao, 2015; Hewett et al., 2016; Hong & Yoo, 2017; Jones et al., 2018; Kim et al., 2005; Leow et al., 2010; McAuliffe et al., 2017; Pierce et al., 2016; Song et al., 2019; Tabor et al., 2016; Turley & Cohen, 2009; van Hooren et al., 2016; Vogel et al., 2014) (c) (Carneiro et al., 2013; Carneiro et al., 2014; Kim et al., 2005; Leow et al., 2010; Plowman-Prine et al., 2009; Pontes et al., 2017; van Hooren et al., 2016)[38, 58, 67, 73-76] (d) (Carneiro et al., 2013; Chen et al., 2009; Colpaert et al., 2017; Diniz et al., 2018; Eslick & Talley, 2008; Finger et al., 2019; Hellden et al., 2018; Jones et al., 2018; Klugman & Ross, 2002; LaDonna et al., 2016; Leow et al., 2010; Luchesi & Silveira, 2018; Mahant et al., 2011; Manor et al., 2018; Moloney & Walshe, 2019; Morisaki, 2017; Paris et al., 2013; Pierce et al., 2016; Pitts et al., 2019; Pontes et al., 2017; Printza et al., 2020; Roy et al., 2007; Roy et al., 2018; Vogel et al., 2017)
Dysphagia therapy effects on quality of life (a) No difference between different therapies on quality of life (b) Therapy had no impact on quality of life (c) Therapy improved quality of life (d) Therapy had a negative impact on quality of life (e) Self-taught methods to improve quality of life (f) Therapy recommendations	(1)Biological function (2) symptoms (3) functional status (4) general health perceptions (5) overall quality of life.	(a) (Heijnen et al., 2012; Kelly et al., 2013; Moon et al., 2018; Reyes et al., 2015; Sundstedt et al., 2016; Unluer et al., 2019) (b) (Balandin et al., 2009; Hagglund et al., 2019; Milte et al., 2017; Reyes et al., 2015; Sundstedt et al., 2016) (c) (Argolo et al., 2013; Athukorala et al., 2014; Ayres et al., 2017; Ayres et al., 2016; Bahceci et al., 2017; Chen et al., 2018; Colpaert et al., 2017; Frost et al., 2018; Heijnen et al., 2012; Jin et al., 2020; Kang et al., 2012; Karagiannis & Karagiannis, 2014; Liu et al., 2018; Liu et al., 2019; Malandraki et al., 2016; Manor et al., 2013; Moon et al., 2019; Rogus-Pulia et al., 2016; Sanchez-Kuhn et al., 2019; Tarlarini et al., 2019; Unluer et al., 2019; Verin et al., 2011; Vieira et al., 2018; Xia et al., 2016; Zhang et al., 2016). (d) (Ang et al., 2019; Mahant et al., 2011; Moloney & Walshe, 2018; Shune & Linville, 2019; Stavroulakis et al., 2016; Swan et al., 2015; Tarlarini et al., 2019) (e) (Balandin et al., 2009; Moloney & Walshe, 2018; Seshadri et al., 2018; Shune & Linville, 2019) (f) (Balandin et al., 2009; Malandraki et al., 2014; Moloney & Walshe, 2018; Shune & Linville, 2019; Tarlarini et al., 2019)

Table 2

Participant Quotes Regarding Dysphagia and Quality of Life Themes

Theme	Subtheme	Quotes
Attempts to maintain quality of life	Eating regular food	"When the sacrifice became too burdensome, they abandoned the recommended diet modification and reverted to regular softer foods with his wife 'watching him like a hawk'." (Seshadri et al., 2018, p. 754).
Biopsychosocial response	Fatigue	Miles said: "Last year I noticed there was a slight change in how I feed myself, my movement in my wrist and my shoulder and my elbow, I'm getting more stiffer." (Balandin et al., 2009, p. 201)
	Increased time to eat	"Almost everyone finishes before me and there is no time left for leisure." (Remijn et al., 2019, p. 1901)
	Reduced desire to eat	"I sometimes think, 'Oh, I feel like an apple', but it takes so long to eat. So, leave it." (Remijn et al., 2019, p. 1901)
Emotional response to dysphagia	Frustration	"It's harder, when you gotta watch other people eat what you'd like." (Balandin et al., 2009, p. 202)
	Humiliation	"It's embarrassing if you go out to a meal . . . Yes, I mean, people look at you." (Medin et al., 2010, p. 1350)
	Loss	"I used to love cooking. For my husband and the grandchildren. Now I can't do it. Nanny's body's just cracking up on her." (Perry & McLaren, 2003, p. 190)
	Feelings of incompetence	Fearing loss of ability to feed self "while you can feed yourself you can gauge what you, how much you put on the spoon, but when you are being fed by somebody else they gauge it for you." (Balandin et al., 2009, p. 201)
Impact on families and carers	New role for family member	"Siblings had roles in caregiving, such as with tube feeding. The needs of their disabled sibling were seen to limit other activities (e.g., recreation, time with parents)" (Mahant et al., 2011, p. e399)
	Avoidance of eating at social situations	"I do not want people to be bothered by having me for a visit" (Klinke et al., 2013, p. 255)
	Treatment by others	". . . you get the sarcastic looks, they see you … walking with this tube hanging around [your child]." (Mahant et al., 2011, p. e398)

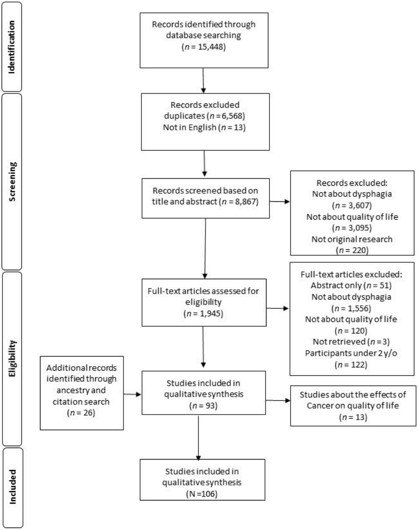
Social and work isolation	Comorbid communication difficulties	“None of the six participants who used communication boards had access to their boards during meals.” (Balandin et al., 2009, p. 203)
	Loss of independence	“Not only would Emma (wife) have to feed me, which was undignified enough, but I would be eating with my mouth open and also, no doubt, be coughing on my food.” (Moloney & Walshe, 2018, p. 1528)
	Reduced participation	“Residents desired to eat in good company and be among friends, rather than be restricted to sitting by ‘diagnosis’.” (Shune & Linville, 2019, p. 149)
	Saving face	“Some participants pretended to drink coffee, lifted their cups to their mouths and took sips without swallowing. This was an attempt to maintain normal cadence in socialising.” (Klinke et al., 2014, p. 6)
Dysphagia therapy effects	Therapy had a negative impact on quality of life	“[Modified food] makes them feel less normal. Like they’re different or they’re . . . almost like childish.” (Shune & Linville, 2019, p. 149)
	Self-taught methods	Participants could eat regular food that was prepared in a specific way “I would have normal meals, like lamb or chicken, pork, it has to be quite tender, if it’s too hard I will choke, cough.” (Balandin et al., 2009, p. 200)
	Therapy recommendations	“Successful dining for residents with dysphagia is reliant upon residents being valued as individuals with their own individual needs.” (Shune & Linville, 2019, p. 148)

Supplemental Material S1. Medline search strategy for systematic review.

Search terms
1. dysphagia.mp. or Deglutition Disorders/
2. deglutition disorder.mp.
3. swallowing disorder.mp.
4. choking.mp. or Airway Obstruction/
5. Feeding Methods/ or feeding.mp.
6. eating.mp. or Eating/
7. swallowing impairment.mp.
8. swallowing therapy.mp.
9. quality of life.mp. or "Quality of Life"/
10. enjoyment.mp.
11. participation.mp. or Patient Participation/ or Community Participation/ or Stakeholder Participation/ or Social Participation/
12. inclusion.mp.
13. self-determination.mp. or Personal Autonomy/
14. "Activities of Daily Living"/ or independence.mp.
15. Personal Autonomy/ or autonomy.mp.
16. community participation.mp.
17. patient participation.mp.
18. social inclusion.mp.
19. social participation.mp. or Interpersonal Relations/
20. Mental Health/ or wellbeing.mp.
21. lifestyle.mp. or Life Style/
22. Anxiety/ or avoidance.mp.
23. distress.mp.
24. depression.mp. or Depression/
25. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
26. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
27. 25 and 26

S2

PRISMA Flowchart of Inclusion Process Adapted From Moher et al. (2009)



S3

Description of Included Studies

References and type of study	Relevant aim	Number of participants (N), group, age, and cause of dysphagia	QoL assessment used/ data collection tool	Treatment received (treatment group)	QATSDD score (%)
(Gustafsson & Theorell, 1995) QUANT Cross-sectional (Child)	Dysphagia management strategies.	87 people with dysphagia; 16-36 years; cause not specified.	Questionnaire	-	33/42 (79%)
(Mahant et al., 2011) QUAL Case Series (Child)	Impact of GJT or fundoplication.	16 parents of children with GJT or fundoplication and neurological impairment.	Interviews	GJT and fundoplication tube feeding.	34/42 (81%)
(Malandraki et al., 2014) QUANT Case Study (Child)	Effectiveness of therapy via telehealth.	1 child 6 years; Optiz BBB/G Syndrome and Asperger's Syndrome.	EAT-10	Intensive paediatric swallowing telepractice program. One-hour sessions twice a week.	31/42 (74%)
(Remijn et al., 2019) QUAL Cross-sectional (Child)	How dysphagia with CP impacts participation.	10 participants aged 15-23; CP.	Interviews	-	30/42 (71%)
(Alali et al., 2018) QUANT Cross-sectional	Impact of dysphagia on QoL.	103 adults with MS	SWAL-QoL and EAT-10	-	36/42 (86%)
(Arslan et al., 2019) QUANT Cross-sectional	Impact of dysphagia on QoL.	84 adults with a neurological disorder	SWAL-QoL and EAT-10	-	22/42 (52%)
(Aruga et al., 2018) QUANT Case Series	Usefulness of Kuchi-kara Taberu Index Chart	3 adults with dysphagia; mixed causes	Kuchi-kara Taberu Index	-	20/42 (50%)

(Balandin et al., 2009) QUAL Cross-sectional	People's experiences with dysphagia.	32 adults with CP	Interviews	-	29/42 (69%)
(Byeon, 2019) QUANT Cross-sectional	Factors impacting swallowing QoL.	142 adults with age related dysphagia.	SWAL-QoL	-	32/42 (76%)
(Carlozzi et al., 2016) QUANT Diagnostic Accuracy test	Swallowing QoL test for Huntington's Disease.	507 adults with Huntington's disease	HDQLIFE Measure	-	38/42 (90%)
(Carlsson et al., 2004) QUAL Case series	Experiences of dysphagia after a CVA.	3 adults with dysphagia after CVA	Interviews and mealtime observations	-	27/42 (64%)
(Carneiro et al., 2014) QUANT Case-control	Swallowing QoL in PD	62 with PD and 41 controls.	SWAL-QoL	-	32/42 (76%)
(Chen et al., 2009) QUANT Cross-sectional	Dysphagia and QoL in a geriatric population.	107 adults with age related dysphagia	MDADI and SF-12	-	32/42 (76%)
(Da Costa Franceschini & Mourao, 2015) QUANT Cross-sectional	Dysphagia and QoL in ALS.	17 adults with ALS	SWAL-QoL	-	33/42 (79%)
(de Faria Gaspar et al., 2015) QUANT Cross-sectional	QoL and dysphagia after CVA.	35 adults with dysphagia (9 tube fed); CVA	SWAL-QoL	-	31/42 (74%)
(Diniz et al., 2018) QUANT Diagnostic case control	Assessment for swallowing QoL in PD.	140 adults with dysphagia; PD, 47 controls.	SWAL-QoL	-	35/42 (83%)

(Ekberg et al., 2002) Mixed Cross-sectional	Effects of dysphagia on QOL.	360 adults with dysphagia; mixed causes; 28 health professionals.	DGH Scale and interviews	-	25/48 (52%)
(Eslick & Talley, 2008) QUANT Cross- sectional	Impact of dysphagia on the community.	672 adults with dysphagia; mixed causes.	CPQ	-	35/42 (83%)
(Farri et al., 2007) QUANT Cross-sectional	Impact of dysphagia on QoL.	73 adults with dysphagia from surgery.	DGH Scale	-	21/42 (50%)
(Finger et al., 2019) QUANT Cross-sectional	Onset of patient reported dysphagia symptoms.	268 adults with dysphagia; mixed causes.	EAT-10	-	34/42 (81%)
(Hellden et al., 2018) QUAL Cross-sectional	Experiences of dysphagia after CVA.	5 adults with dysphagia; CVA.	Interviews		33/42 (79%)
(Hewett et al., 2016) QUANT Case-control	QoL in people with EOE.	44 adults with dysphagia; EOE; 44 controls.	EOE Adult Quality of Life Questionnaire	-	33/42 (79%)
(Hong & Yoo, 2017) QUANT Cross-sectional	Swallowing QoL in patients with CVA.	79 adults with dysphagia; CVA; (*n*= 35 non-oral intake).	SWAL-QoL	-	25/42 (60%)
(Jacobsson et al., 2000) Mixed Case-control	Experiences of eating after a CVA.	30 adults; CVA; 15 controls.	Interviews and mealtime observations.	-	24/48 (50%)
(Johansson & Johansson, 2009) QUAL Cross-sectional	Experiences of relatives involved with dysphagia.	9 relatives of adults with dysphagia; mixed causes.	Interviews	-	31/42 (74%)

(Kim et al., 2005) QUANT Cohort study	Swallowing of young and older people with CVA.	96 young CVA onset participants, 160 old CVA onset participants.	SS-QoL	-	39/42 (93%)
(Klinke et al., 2014) QUAL Cross-sectional	Experiences of dysphagia after CVA.	7 adults with dysphagia; CVA.	Interviews	-	30/42 (71%)
(Klugman & Ross, 2002) Mixed Cross-sectional	Perceptions of dysphagia and their impact on QoL.	30 adults; MS.	Questionnaire	-	28/48 (67%)
(LaDonna et al., 2016) QUAL Cross-sectional	Experiences of relatives living with people with dysphagia.	6 relatives of adults with dysphagia; DM1.	Interviews	-	32/42 (76%)
(Leow et al., 2010) QUANT Cross-sectional	Impact of dysphagia on QoL for elderly and people with PD.	32 adults with PD, 16 elderly people, 16 young controls.	SWAL-QoL	-	31/42 (74%)
(Luchesi & Silveira, 2018) Mixed Case series	The importance of oral feeding in ALS.	4 adults; ALS.	Interview and SWAL-QoL	-	24/42 (57%)
(Manor et al., 2019) QUANT Case series	The link between FEES results and QoL.	14 adults; Huntington’s disease.	SWAL-QoL and SDQ	-	29/42 (69%)
(Martino et al., 2010)QUAL Cross-sectional	Psychological issues in people with acute or chronic dysphagia.	8 adults (3 acute and 5 chronic); dysphagia of mixed causes,	Focus groups	-	31/42 (74%)

(McAuliffe et al., 2017) QUANT Cross-sectional	Variables of participation in PD.	378 adults; PD.	CPIB	-	33/42 (79%)
(Medin, Larson, et al., 2010) QUAL Cross-sectional	Experiences of eating difficulties 3 months post CVA.	14 adults; 3 months post CVA.	Semi-structured interviews	-	33/42 (79%)
(Medin, Windahl, et al., 2010) QUAL Cross-sectional	Management of eating 6 months post CVA.	13 adults; 6 months post CVA.	Semi-structured interviews	-	31/42 (74%)
(Miller et al., 2006) QUAL Case series	How dysphagia impacts on QoL in PD.	37 adults; PD.	Interviews	-	28/42 (67%)
(Milte et al., 2017) QUAL Case series	Dining experiences for participants and carers.	19 adults;Cognitive impairment or dementia.	Interviews and focus groups	-	31/42 (74%)
(Moloney & Walshe, 2018) QUAL Case series	Experiences of dysphagia after a CVA.	10 adults with dysphagia; CVA.	Phenomenological analysis of published autobiographies	-	30/42 (71%)
(Moloney & Walshe, 2019)Mixed Cross-sectional	Speech-language pathology management QoL in dysphagia.	148 speech-language pathologists.	Original questionnaire	-	36/48 (75%)
(Morisaki, 2017) QUANT	Swallow function and QoL.	225 adults with dysphagia; no specific cause.	DRACE and the SF-8	-	38/42 (90%)

Cross-sectional					
(Nyberg et al., 2018) QUAL Cross-sectional	How people with dysphagia perceive mealtimes.	14 adults; mixed dysphagia causes.	Interviews and mealtime observations	-	29/42 (69%)
(Paris et al., 2013) QUANT Cohort study	Impact of dysphagia on QoL with ALS.	14 adults; ALS; 16 controls.	SWAL-QoL	-	28/42 (67%)
(Perry & McLaren, 2003)QUAL Cross-sectional	Perceptions to eating after a CVA.	206 people, includes 10 carers; CVA.	Semi-structured interviews		29/42 (69%)
(Pierce et al., 2016) QUANT Cross-sectional	Social, emotional, and functional impacts of dysphagia.	101 adults; Sjogren's syndrome.	MDADI, SF-36	-	31/42 (74%)
(Pitts et al., 2019) QUANT Cross-sectional	Link between lingual pressure and swallowing QoL in PD.	24 adults; PD; 24 controls.	SWAL-QoL, and the test of interior and tongue strength	-	28/42 (67%)
(Plowman-Prine et al., 2009) QUANT Cross-sectional	Swallowing QoL in IPD.	36 adults; IPD.	SWAL-QoL, and PDQ-39	-	22/42 (52%)
QUANT (Pontes et al., 2017) Cross-sectional	QoL of elderly with dysphagia after a CVA.	35 participants; CVA.	SWAL-QoL	-	24/42 (57%)
(Printza et al., 2020) QUANT	Dysphagia perceptions, and QoL in MS.	108 adults (*n* = 27 with dysphagia); MS.	SWAL-QoL, EAT-10, and DYMUS	-	32/42 (76%)

Cross-sectional					
(Roy et al., 2007) QUANT Cross-sectional	Socioemotional effects of dysphagia.	117 participants, 44 with dysphagia; mixed causes.	MDADI	-	28/42 (67%)
(Roy et al., 2018) QUANT Cross-sectional	QOL and dysphagia in Rheumatoid Arthritis.	100 participants; Rheumatoid Arthritis.	MDADI and the SF-36		32/42 (76%)
(Shune & Linville, 2019) QUAL Cross-sectional	Mealtime safety and enjoyment in dysphagia.	3 residents with dysphagia; mixed causes; 3 family members, 6 nurses, 3 dietary staff, 3 speech-language pathologists, 3 occupational therapists.	Interviews	-	36/42 (86%)
(Song et al., 2020) QUANT Case-series	Dysphagia in X linked dystonia parkinsonism and QoL.	34 adults; X linked dystonia parkinsonism.	SWAL-QoL	-	29/42 (69%)
(Tabor et al., 2016) QUANT Case-series	Dysphagia impacts on QoL in ALS.	81 adults; ALS.	SWAL-QoL and ALSFRS-R	-	24/42 (57%)
(Tibbling & Gustafsson, 1991) QUANT Cohort-study	Dysphagia impacts on QoL in the elderly.	796 adults; dysphagia of no specific cause.	Questionnaire	-	28/42 (67%)
(Turley & Cohen, 2009) QUANT Cross-sectional	QoL impacts of dysphagia in the elderly.	248 adults with dysphagia; cause not specified.	VRQOL and CES-D	-	30/42 (71%)

(van Hooren et al., 2016) QUANT Case series	Swallowing-related QoL and IPD.	100 adults; IDP.	MDADI, DSS and VHI	-	31/42 (74%)
(Verdonschot et al., 2016) QUANT Cohort-study	Link between dysphagia and affective symptoms.	107 adults; mixed dysphagia causes.	HADS, FEES, and DSS	-	27/42 (64%)
(Verdonschot et al., 2013) QUANT Cohort-study	Severity of anxiety and depression in dysphagia.	96 adults; mixed dysphagia causes.	HADS, FEES, DSS, MDADI, and FOIS	-	30/42 (71%)
(Vogel et al., 2014) QUANT Cohort study	Dysphagia and QoL in Friedreich ataxia.	36 adults; Friedreich ataxia.	AusTOMS	-	31/42 (74%)
(Vogel et al., 2017) Mixed Cohort-study	Dysphagia and QoL in POLG.	14 adults with POLG, 34 controls.	SWAL-QoL	-	29/42 (69%)
(Wegner et al., 2018) QUANT Cross-sectional	Swallowing-related QoL and COPD.	17 adults; COPD.	SWAL-QoL	-	31/42 (74%)
(Yi et al., 2019) QUANT Cross-sectional	Impact of dysphagia on QoL in CP.	117 adults with dysphagia; CP; 117 controls.	SWAL-QoL	-	31/42 (74%)
(Ang et al., 2019) QUAL Cross-sectional	Experiences with long-term enteral tube feeding.	9 adults with dysphagia; mixed causes; 9 carers.	Interviews	Enteral tube feeding.	38/42 (90%)
(Argolo et al., 2013) QUANT Case series	Motor swallowing exercises and QoL in PD.	15 adults; PD.	SWAL-QoL (prior to and post intervention)	Motor swallowing exercises.	28/42 (67%)

(Athukorala et al., 2014) QUANT Case series	Swallowing skill training in PD.	10 adults; PD.	SWAL-QoL (prior to and post intervention)	Task specific exercises with sEMG feedback.	34/42 (81%)
(Ayres et al., 2017) QUANT Cohort study	Effectiveness of manoeuvre application in PD.	24 adults (divided into 3 treatment grousp); PD.	SWAL-QoL (prior to and post intervention)	1. Chin tuck manoeuvre 2. Environmental and 3. Postural information vs control.	36/42 (86%)
(Ayres et al., 2016) QUANT Case series	QOL in PD before and after swallowing therapy.	10 adults; PD	SWAL-QoL (prior to and post intervention)	Chin tuck and guidelines on mealtime behaviours.	25/42 (60%)
(Bahceci et al., 2017) QUANT Case series	Relationship between swallowing and QoL after a CVA.	72 adults between 0-30 days post CVA.	SWAL-QoL (prior to and post intervention)	Oral hygiene, head/trunk positioning, oro-motor exercises, galvanic stimulation.	33/42 (79%)
(Chen et al., 2018) QUANT Cohort study	Effects of swallowing exercises on the QoL of oral cancer patients.	76 adults (split equally into control and experimental group); head/neck cancer.	MDADI and SSQ (prior to and post intervention)	1. Swallowing exercise education program. 2. Usual care.	37/42 (88%)
(Colpaert et al., 2017) QUANT Case series	Use SWAL-QoL to examine dysphagia in Zenker's diverticulum.	25 participants (17 had dysphagia); Zenker's diverticulum.	SWAL-QoL (prior to and post intervention)	Surgery to repair diverticulum.	34/42 (81%)
(Frost et al., 2018) QUANT Case series	Improve oral intake with traditional swallowing therapy and NMES.	10 adults with dysphagia; non-specified cause.	SWAL-QoL and EAT-10 Prior to, mid, and post intervention).	NMES and traditional swallowing therapy.	33/42 (79%)
(Hagglund et al., 2019) QUANT RCT	Impact of oral neuromuscular training on swallowing.	116 adults, dysphagia of non-specified cause.	SWAL-QoL (prior to and post intervention)	Neuromuscular training using the IQoro device.	33/42 (79%)
(Heijnen et al., 2012) QUANT Pseudo-RCT	Compare traditional swallowing therapy to NMES therapy and QoL.	88 adults (divided into 3 treatment groups); PD.	SWAL-QoL and MDADI (prior to and post intervention)	1. Traditional logopedic swallowing therapy 2. Traditional logopedic swallowing therapy and NMES at motor level. 3. Traditional	36/42 (86%)

				logopedic swallowing therapy and NMES at sensory level.	
(Jin et al., 2020) QUANT Case series	Impact of CAECPM on swallowing QoL.	19 adults; CVA or lateral skull surgery.	CSWAL-QoL	CAECPM.	29/42 (69%)
(Kang et al., 2012) QUANT Non-RCT	Exercise program to improve swallowing after CVA.	50 adults (split equally into control and experimental group); CVA.	SS-QoL assessment (prior to and post intervention)	1. Traditional swallowing therapy 2. Oral, pharyngeal, laryngeal and respiratory exercises and traditional swallowing therapy.	30/42 (71%)
(Karagiannis & Karagiannis, 2014) QUANT Case series	Relationship between access to water and QoL.	16 adults with dysphagia; mixed causes.	4 question survey using faces rating chart	Fraizier Rehabilitation Centre Free Water Protocol and thickened fluids.	31/42 (74%)
(Kelly et al., 2013) QUANT Case series	QoL after botulinum toxin injections.	49 adults with UES.	EAT-10 (prior to and post intervention)	Cricopharyngeal botulinum toxin injections.	29/42 (69%)
(Liu et al., 2018) QUANT RCT	Compare nape acupuncture and rehabilitative swallowing therapy impacts on QoL.	100 adults (split equally into control and experimental group); pseudobulbar palsy.	SWAL-QoL (prior to and post intervention)	1. Nape acupuncture and rehabilitative swallowing training. 2. Rehabilitative swallowing training.	32/42 (76%)
(Liu et al., 2019) QUANT RCT	Impact of Gao nape acupuncture and swallowing training after a CVA.	100 adults (split equally into control and experimental group); CVA.	SWAL-QoL (prior to and post intervention)	1. Gao’s nape acupuncture and rehabilitative swallowing training. 2. Rehabilitative swallowing training.	26/42 (62%)
(Malandraki et al., 2016) QUANT Case series	Impact on intensive dysphagia rehabilitative training on swallowing.	10 adults; neurological disease or injury.	EAT-10 (prior to and post intervention)	Intensive dysphagia rehabilitative training protocol.	32/42 (76%)
(Manor et al., 2013) QUANT RCT	Compare VAST to traditional swallowing therapy.	42 adults, (split equally into control and experimental group); PD.	SWAL-QoL (prior to and post intervention)	1. VAST. 2. Traditional dysphagia therapy.	30/42 (71%)

(Moon et al., 2018) QUANT RCT	Impact of TPSAT on QoL after a CVA.	16 adults (split equally into control and experimental group); CVA.	SWAL-QoL (prior to and post intervention)	1. TPSAT and traditional swallowing therapy. 2. Traditional swallowing therapy.	36/42 (86%)
(Reyes et al., 2015) QUANT RCT	Effects of respiratory muscle training on swallowing.	18 adults (split equally into control and experimental group); Huntington's disease	SWAL-QoL (prior to and post intervention)	Inspiratory and expiratory muscle training against progressive (experimental) or fixed (control) resistance.	32/42 (76%)
(Rogus-Pulia et al., 2016) QUANT Case series	Use of Swallow STRONG to improve swallowing QOL	56 adults; dysphagia of no specified cause.	SWAL-QoL (prior to, mid, and post intervention)	Swallow STRONG using isometric progressive resistance oropharyngeal therapy.	32/42 (76%)
(Sanchez-Kuhn et al., 2019) QUANT Case study	tDCS with swallowing training after CVA.	1 adult; CVA.	SWAL-QoL (prior to and post intervention)	tDCS.	23/42 (55%)
(Seshadri et al., 2018)QUAL Cross-sectional	Texture modified diet with lifestyle.	20 adults; dysphagia of mixed causes.	Interviews and mealtime observations	Texture modified diet.	33/42 (79%)
(Stavroulakis et al., 2016) QUAL Cross-sectional	Gastrostomy experiences of patients and carers.	18 adults, 10 patients and 10 carers; MND	Interview three months post-surgery	Gastrostomy.	37/42 (88%)
(Sundstedt et al., 2016) QUANT Case control	Impact of deep brain stimulation on swallowing.	9 adults with PD; 9 healthy controls.	SWAL-QoL (prior to and post intervention)	Caudal zona incerta deep brain stimulation.	30/42 (71%)
(Tarlarini et al., 2019) QUANT Case-series	Taste changes and QoL in ALS	21 oral fed participants and 10 enteral tube fed participants; ALS.	UW-QOLQ	Device that provides selected flavours to foods.	30/42 (71%)

(Unluer et al., 2019) QUANT RCT	rTMS impacts on swallowing and QoL.	28 adults, 15 in experimental and 13 in control group; CVA.	SWAL-QoL (prior to and post intervention)	1. rTMS and traditional swallow therapy. 2. Traditional swallow therapy.	34/42 (81%)
(Verin et al., 2011) QUANT Case series	Use of SSTES to improve swallowing.	13 adults; neurological disorders.	SWAL-QoL (prior to and post intervention)	SSTES for six weeks.	26/42 (62%)
(Vieira et al., 2018) QUANT Non-RCT	Impact of texture modified diet on QoL.	25 adults, 12 at risk of dysphagia; CVA	SWAL-QoL (prior to and post intervention)	1. Traditional swallow therapy and texture modified food. 2. Traditional swallow therapy.	26/42 (61%)
(Xia et al., 2016) QUANT RCT	Acupuncture and traditional swallowing therapy for dysphagia.	124 adults, (split into control and experimental group); CVA.	SWAL-QoL (prior to and post intervention)	1. Acupuncture and traditional swallowing therapy. 2. Traditional swallowing therapy.	36/42 (86%)
(Zhang et al., 2016) QUANT RCT	NMES motor and sensory impacts on dysphagia.	82 adults (divided into 3 treatment groups); medullary infarction.	SWAL-QoL (prior to and post intervention)	1. Traditional swallow therapy. 2. Traditional swallow therapy and motor NMES. 3. Traditional swallow therapy and sensory NMES.	30/42 (71%)
(McHorney, Bricker, Kramer, et al., 2000) QUAL Cross-sectional	Conceptual foundation for the SWAL-QoL.	52 adults; dysphagia of mixed causes.	Focus groups	-	37/42 (88%)
(McHorney, Bricker, Robbins, et al., 2000) QUANT Diagnostic accuracy	SWAL-QoL reliability and range of skewness.	106 adults with mixed dysphagia causes.	SWAL-QoL	-	35/42 (83%)
(McHorney et al., 2002) QUANT	Report on reliability of SWAL-QoL and SWAL-CARE.	386 adults; dysphagia of mixed causes; 40 controls.	SWAL-QoL	-	37/42 (88%)

Diagnostic case control

*Note. Amyotrophic lateral sclerosis (*ALS), *Amyotrophic Lateral Sclerosis* Functional Rating Scale-Revised (ALSFRS-R), Australian Therapy Outcome Measures for Speech and Swallowing (AusTOMS), Centre of Epidemiological Studies Depression Scale (CES-D), cerebral palsy (CP), cerebrovascular accident (CVA) Chest Pain Questionnaire (CPQ), Chinese Version of the Swallowing Quality of Life Questionnaire (CSWAL-QoL), chronic obstructive pulmonary disease (COPD), coblation-assisted endoscopic cricopharyngeal myotomy (CAECPM), Communicative Participation Item Bank (CPIB), Disability-Goal-Handicap Scale (DGH Scale), Dysphagia in Multiple Sclerosis (DYMUS), Dysphagia Risk Assessment for Community Dwelling Elderly (DRACE), Dysphagia Severity Scale (DSS), Eating Assessment Tool (EAT-10), eosinophilic oesophagitis (EOE), fibreoptic endoscopic evaluation of swallowing (FEES), Functional Oral Intake Scale (FOIS), gastrojejunostomy tube (GJT), Hospital Anxiety and Depression Scale (HADS), Huntington Disease Health Related Quality of Life Measure (HDQLIFE), idiopathic Parkinson's disease (IPD), M.D. Anderson Dysphagia Inventory (MDADI), mitochondiral DNA polymerase gamma (POLG), motor neuron disease (MND), *multiple sclerosis (*MS), neuromuscular electrical stimulation (NMES), non- randomized control trial (non-RCT), Parkinson's Disease (PD), Parkinson's Disease Questionnaire-39 (PDQ-39), qualitative study (QUAL), Quality of Care in Swallowing Disorders Survey (SWAL-CARE), quality of life (QOL), quantitative study (QUANT), randomized control trial (RCT), repetitive transcranial magnetic stimulation (rTMS), Short Form Health Survey 8 (SF-8), Short Form Health Survey 12v2 (SF-12), Short Form Health Survey 36 (SF-36), Stoke Specific Quality of Life Assessment (SS-QOL), submental sensitive transcutaneous electrical stimulation (SSTES), surface electromyography (sEMG), Swallow Strengthening Oropharyngeal Program (Swallow STRONG), Swallowing Quality of Life Questionnaire (SWAL-QoL), Sydney Swallowing Questionnaire (SSQ), systematic review (SR), tongue pressure strength and accuracy training (TPSAT), transcortical direct current stimulation (tDCS), University of Washington Quality of Life Questionaire-4 (UW-QOLQ), video-assisted swallowing therapy (VAST), Voice Handicap Index (VHI), Voice Related Quality of Life (VRQOL).

Supplemental Material S4. Analysis of review studies.

Reference	**Aim**	**Included studies**	**Population included**	**Limitations/gaps in the review**
Carneiro et al., 2013	SWAL-QoL and Parkinson’s	2 cohort studies	People with dysphagia resulting from Parkinson’s	Only included 2 studies, included studies specifically about the SWAL-QoL and dysphagia resulting from Parkinson’s.
Jones et al., 2018	HRQoL and oropharyngeal dysphagia	35 studies (31 case series and 4 pseudorandomized)	People with oropharyngeal dysphagia; mixed causes of dysphagia: neck cancer, CVA, Parkinson’s	Papers only included if in English, oesophageal dysphagia was excluded, and authors of included studies were not contacted.
Katzberg & Benatar, 2011	PEG and QoL in ALS	11 non-RCTs and 4 case control studies	People with ALS or MND	Did not include dysphagia of other causes, and only looked at the impact of tube feeding.
Klinke et al., 2013	Views on eating difficulties after a CVA	33 case studies and case series studies	People with dysphagia after CVA	Quality of results was based on the types of analytical questions asked, and only included participants with dysphagia after CVA.
Langmore et al., 2006	PEG and QoL in ALS	11 case or cohort studies	People with ALS or MND	Uncontrolled studies not included, and only included studies where ALS/MND was the cause of dysphagia.
Li & Deng, 2019	Acupuncture and traditional swallowing therapy	17 RCTs	People with dysphagia post CVA	Heterogeneity and publication bias observed. The long-term curative effects of acupuncture combined with swallowing training could not be evaluated because all of the studies included reported only short-term effects.
Swan et al., 2015	Texture-modified foods and HRQoL	8 studies (2 RCTs and 6 non-RCTs)	People with oropharyngeal dysphagia; mixed causes	Small number of studies, the heterogeneity of population, the study design, lack of standardized terminology.
Verdonschot et al., 2017	Oropharyngeal dysphagia and depression/ anxiety	24 studies (15 cross sectional, 5 prospective, 2 retrospective, and 2 case control studies)	People with oropharyngeal dysphagia; mixed causes: CVA, cancer	Search strategy included mesh terms and limited free-text terms and grey literature was not included.

Note. Amyotrophic lateral sclerosis (ALS), cerebrovascular accident (CVA), health related quality of life (HRQoL), motor neuron disease *(*MND), non- randomized control trial (non-RCT), percutaneous endoscopic gastrostomy (PEG) quality of life (QoL), randomized control trial (RCT) Swallowing Quality of Life Questionnaire (SWAL-QoL)

Supplemental Material S5. Assessment items implemented for quality of life.

Assessment implemented	Study
Assessment items examining either quality of life or a domain of quality of life	
SWAL-QoL	Alali et al., 2018; Argolo et al., 2013; Arslan et al., 2019; Athukorala et al., 2014; Ayres et al., 2017; Ayres et al., 2016; Bahceci et al., 2017; Byeon, 2019; Carneiro et al., 2014; Colpaert et al., 2017; Da Costa Franceschini & Mourao, 2015; de Faria Gaspar et al., 2015; Diniz et al., 2018; Frost et al., 2018; Hagglund et al., 2019; Heijnen et al., 2012; Hong & Yoo, 2017; Jin et al., 2020; Leow et al., 2010; Liu et al., 2018; Liu et al., 2019; Luchesi & Silveira, 2018; Manor et al., 2013; Manor et al., 2018; Moon et al., 2018; Paris et al., 2013; Pitts et al., 2019; Plowman-Prine et al., 2009; Pontes et al., 2017; Printza et al., 2020; Reyes et al., 2015; Rogus-Pulia et al., 2016; Sanchez-Kuhn et al., 2019; Song et al., 2020; Sundstedt et al., 2016; Tabor et al., 2016; Unluer et al., 2019; Verin et al., 2011; Vieira et al., 2018; Vogel et al., 2017; Wegner et al., 2018; Xia et al., 2016; Yi et al., 2019; Zhang et al., 2016
EAT-10	Alali et al., 2018; Arslan et al., 2019; Finger et al., 2019; Frost et al., 2018; Kelly et al., 2013; Malandraki et al., 2016; Malandraki et al., 2014; Printza et al., 2020
Kuchi-kara Taberu Index	Aruga et al., 2018
Disability-Goal-Handicap Scale	Ekberg et al., 2002; Farri et al., 2007
Hospital Anxiety and Depression Scale	Chen et al., 2018; Verdonschot et al., 2016
Functional Oral Intake Scale	Verdonschot et al., 2013
Chest Pain Questionnaire	Eslick & Talley, 2008
Swallowing Disturbance Questionnaire	Manor et al., 2018
Sydney Swallowing Questionnaire	Chen et al., 2018
Communicative Participation Item Bank	McAuliffe et al., 2017
Dysphagia Risk Assessment for Community Dwelling Elderly	Morisaki, 2017
Short Form Health Survey (SF-8, SF-12, SF-36)	Chen et al., 2009; Morisaki, 2017; Roy et al., 2018
M.D. Anderson Dysphagia Inventory	Chen et al., 2009; Chen et al., 2018; Roy et al., 2007; Roy et al., 2018
Australian Therapy Outcome Measures for Speech and Swallowing	Vogel et al., 2014
Voice Related Quality of Life	Turley & Cohen, 2009
Centre of Epidemiological Studies Depression Scale (CES-D)	Turley & Cohen, 2009
Condition specific assessments examining quality of life	
Huntington Disease Health Related Quality of Life (HDQLIFE) Measure	Carlozzi et al., 2016
The Eosinophilic esophagitis (EOE) Adult Quality of Life Questionnaire	Hewett et al., 2016
Parkinson’s Disease Questionnaire-39 (PDQ-39)	Plowman-Prine et al., 2009
Stoke Specific Quality of Life assessment (SS-QoL)	Kang et al., 2012

Supplemental Material S6. Studies found in August 2020.

Study	Aim	Population	Method	Result
Byeon, 2020	Effects of Mendelsohn manoeuvre and NMES on swallowing and QoL	*N* = 43, CVA	Swallow assessed using FDS and QoL assessed using SWAL-QoL	Participants who had both NMES and Mendelsohn had highest FDS and SWAL-QoL scores than participants who had one therapy.
Chan et al., 2020	QoL in patients with PD using the CSWAL-QoL	*N* = 67, PD	The CSWAL-QoL and Geriatric Depression Scale to assess QoL and depression	Sleep, fatigue, eating duration and communication were the most severely affected by PD. Significant link between swallowing and depression.
Covello et al., 2020	Evaluate the oral health status, dysphagia, and QoL of people with MS	*N* = 101, MS	Assessed on DYMUS and the OHIP-14	15% of people needed to pause when eating, 25% had difficulty swallowing. Dysphagia impacted on QoL "although not more than the disease itself."
Kim et al., 2019	Meaning of life impacts on the relationship between depression and QoL in people with dysphagia?	*N* = 90, CVA, degenerative disease, TBI, or nervous disorder	SWAL-QoL measured QoL, CES-D measured depression, and PIL measured meaning of life	Meaning of life had mediating effect on the QoL and depression of people with dysphagia.
Padilla et al., 2019)	Explore QoL in Hispanic New Mexicans with dysphagia	*N* = 7, CVA, muscle weakness, CP, Guillain-Barré syndrome, TBI	SWAL-QoL, Neuro-QOL, interviews (interviews only with participants with acquired dysphagia).	QoL categorized as an emotional experience (themes: distrust, fear, frustration, acceptance, triggers, and impacts).
Pilz et al., 2020	To describe swallowing related QoL in people with DM1 and examine its association with swallowing and disease severity	*n* = 75 with DM1, *n* = 25 controls; DM1	SWAL-QoL	SWAL-QoL scores were significantly lower for those with DM1 than controls.
Ronnefarth et al., 2020	Determine impacts of dysphagia in cerebellar ataxia patients on QoL	*N* = 119, cerebellar ataxia	SWAL-QoL	Participants with dysphagia had significantly reduced QoL over those without dysphagia.
Shune & Namasivayam	Type/extent of burden felt by older adults caring for their spouse with dysphagia	*N* = 422 older adults with dysphagia and their spouse	National Health and Aging Trends Survey (population-based survey)	Older adults caring for their partners with dysphagia were more likely to feel emotional burden. They also reported feelings of

-MacDonald, 2020				loneliness, depression, financial difficulties, and physical difficulties.
Swales et al., 2020	Participation and psychological impacts of dysphagia and communication difficulties in PD	*N* = 78, PD	Mixed-methods survey	Emotional impacts of swallowing changes: frustration, annoyance, embarrassment, loneliness, depression, anxiety, self-consciousness, adjustment/ acceptance. “don’t enjoy eating out as much…self-conscious in company” (p. 5).
Toledo-Rodríguez et al., 2019	How QoL is perceived in people with neurogenic dysphagia in Chile	*n* = 27, neurogenic dysphagia (CVA, PD, HD, MS, Encephalo-cranial trauma), *n* = 113 controls	SWAL-QoL-CH (Chile)	Participants with dysphagia presented with significant differences in all SWAL-QoL-CH domains.

Note. Centre of Epidemiological Studies Depression Scale (CES-D), cerebral palsy (CP), cerebrovascular accident (CVA), Chinese Version of the Swallowing Quality of Life Questionnaire (CSWAL-QoL), Myotonic Dystrophy (DM1), Dysphagia in Multiple Sclerosis (DYMUS), Functional Dysphagia Scale (FDS), Huntington Disease (HD), Oral Health Impacts Profile (OHIP-14), multiple sclerosis *(*MS), neuromuscular electrical stimulation (NMES), Quality of Life in Neurological Disorders (Neuro-QoL), Parkinson’s Disease (PD), Purpose in Life Test (PIL), quality of life (QOL), Swallowing Quality of Life Questionnaire (SWAL-QoL), Swallowing Quality of Life Questionnaire- Chile (SWAL-QoL-CH), traumatic brain injury (TBI).