

Rapid Review of Speech Pathology Interventions to Improve Participation, Inclusion and Quality of Life for People with Dysphagia

Authors: Lucy Bryant and Bronwyn Hemsley
University of Technology Sydney

SUMMARY

Dysphagia (difficulty swallowing) is associated with a wide range of limitations and restrictions in a person's activities and participation (Nund et al., 2014; O'Halloran & Larkins, 2008; Threats, 2007). However, the main focus of research on dysphagia in individuals with either acquired or lifelong disability has to date focused upon impacts on respiratory health, nutritional health, airway protection and risk of choking, and preventable death. Little is known about whether or how interventions to address these health impacts of dysphagia impact on the lives of individuals with disability and dysphagia, and there is little empirical evidence to guide policy frameworks for funding disability services in relation to dysphagia and mealtimes. Therefore, the aim of this review was to determine: (i) how dysphagia impacts on a child or adult with disability and dysphagia's participation and inclusion, wellbeing, or quality of life; and (ii) the nature of any effects or impacts of dysphagia interventions or other interventions addressing mealtime difficulties, on participation and inclusion, wellbeing, or quality of life, in children or adults with acquired or lifelong disability and dysphagia.

In April 2018, we searched 5 scientific databases and Google Scholar for full papers in English that related to participation, inclusion, and quality of life for children or adults with disability and dysphagia. Any form of disability (acquired, lifelong) including autism spectrum disorder (ASD) was included and no criteria of quality was applied. We sought information on the impact of dysphagia on any aspect of quality of life, wellbeing, participation, or inclusion (i.e., not death, respiratory health, or nutritional health) and on any outcomes of interventions aimed at improving any aspect of dysphagia or mealtimes, on those outcomes. Initially, we focused on searching for literature in the field of speech pathology and located 1157 potentially relevant papers. When few of these papers provided relevant information ($n = 14$, or 1.3%) we expanded the search to include interventions for 'fussy eaters' or individuals with oral hypersensitivities affecting mealtimes, and to other related disciplines involved in mealtime, namely occupational therapy (e.g., mealtime roles, equipment, mealtime assistance), physiotherapy (e.g., mealtime positioning, respiratory health), and education or psychology (e.g., mealtime behaviours). This search located a further 3422 potentially relevant studies, of which only 5 (0.1%) provided relevant information on quality of life, participation, or inclusion outcomes. Thus, in total, from 4579 studies, less than 0.5% provided any outcomes relevant to quality of life, mealtime participation, or inclusion, and the most relevant studies came from the speech pathology literature.

Thus, there is little research evidence yet in the peer reviewed literature on the impacts of dysphagia, or dysphagia-related or mealtime-related interventions, on participation or inclusion, quality of life, or wellbeing in individuals with either acquired or lifelong disability. Most of the 20 studies located related to adults with acquired conditions and did not focus upon mealtime participation and inclusion specifically, but rather more broadly addressed quality of life as measured using tools such as the SWAL-QOL (McHorney et al., 2002), an assessment developed for use with people with stroke. There were few qualitative studies appropriate to understanding the subjective human experiences and lived experience of both dysphagia and its impacts. Studies using the SWAL-QOL (Rogus-Pulia et al., 2016; Stegemoller, Hibbing, Radig, & Wingate, 2017; Zhang et al., 2016) did not capture the detail in outcomes reported in qualitative research involving in-depth interviews with the parents of children with autism (Binnendyk & Lucyshyn, 2009; Cheremshynski, Lucyshyn, & Olson, 2013; Lucyshyn et al., 2007; Muldoon & Cosbey, 2018) and adults with intellectual and developmental disability (Chadwick, Jolliffe, & Goldbart, 2003). The results of this review suggest that foundational qualitative studies, first developing theory on the impact of dysphagia on mealtime participation and inclusion, wellbeing, and quality of life in individuals with disability and dysphagia, and a full appreciation of the experience, are needed to inform further research guiding policies and practice in the management of dysphagia.

BACKGROUND

Impacts of Dysphagia on Mealtime Participation

People with dysphagia often experience not only health impacts related to respiratory health and nutrition, but also social impacts related to limitations and restrictions in their activities relating to eating, drinking, and mealtimes, and to their participation in mealtime routines and cultural practices. In relation to the activity and participation codes within the International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2011), these limitations and restrictions can relate to: d550 eating, d560 drinking, d630 preparing meals, d850 remunerative employment, d9100 informal associations, d9102 ceremonies, d920 recreation and leisure, and d9300 organized religion (Threats, 2007). Adults with cerebral palsy and dysphagia have reported experiencing activity limitations in these areas that impact greatly on their quality of life and enjoyment of meals (Balandin, Hemsley, Hanley, & Sheppard, 2009). Indeed, their limitations in mealtime participation and negative impacts on quality of life related not only to their dysphagia but also to the strategies imposed by speech pathologists through restrictive mealtime plans, designed without their involvement. Even apart from this, adults with cerebral palsy reported making several adaptations to their lifestyle in order to reduce their choking risk and avoid the embarrassment and stigma of coughing and choking. Eating and drinking were a central component of work-related meetings and social events, so having dysphagia and coughing or choking on food, or needing a restricted diet, interrupted their inclusion and participation. Some avoided events that involved both eating and socialising (e.g., Christmas party) or if attending had to choose not to eat or else eat separately for fear of choking. Apart from the safety element, coughing and choking was socially isolating:

Richard (65 years) said that he was 'dreading' eating in public at work events due to his poor saliva control, recurrent coughing, and choking episodes that he found 'humiliating' and 'embarrassing' (Balandin et al., 2009, p. 201).

The increased time needed to eat meals also impacted negatively on mealtime participation, as either staff or dining companions became frustrated at extended mealtimes. As a result, adults with cerebral palsy and dysphagia who wanted to participate in mealtime events felt under some pressure to forego recommendations (e.g., pacing) that would minimise choking and aspiration risk.

In addition to activity limitations, dysphagia also has negative impacts on a person's participation in familial and informal relationships (Westergren, Hagell, Wendin, & Sjödah Hammarlund, 2016). This 'stigma' of dysphagia is also reported by adults with dysphagia who cough or choke or are 'messy eaters' (Balandin et al., 2009; Westergren et al., 2016). In reporting on interviews with people with Parkinson's disease and dysphagia, Westergren et al., (2016) reported stories of isolation and segregation during mealtimes:

When I was about to start eating, the hands were shaking, I could hardly hold the cup and I felt awful when other people looked at me. It felt like everyone was looking at me and thinking 'what a strange person'. So when I was going to eat – I walked away from the others – to find a place to eat on my own. (12L) (p. 203).

People with Parkinson's and dysphagia reported avoiding social activities, especially with new acquaintances due to their dysphagia and the extended time required when eating:

...my husband had to go alone, and it feels tough... hmmm. You avoid inviting new acquaintances in evenings and so on... With those whom I know very well, it's easier... (12L)(p. 203)

Quality of Life and Well-being in Relation to Dysphagia

The issue of 'segregation' and 'isolation' being associated with dysphagia has both health and social impacts, including on wellbeing. There is sufficient evidence now to conclude that dysphagia and mealtime participation interact to impact on a person with dysphagia's social inclusion, wellbeing, and quality of life. In a recent systematic review of studies measuring health-related quality of life in populations with oropharyngeal dysphagia, Jones et al. (2018) reported a consistent inverse relationship between dysphagia and health-related quality of life, in that an increased severity of dysphagia was associated with decreased quality of life. This finding supports the findings of research on diet and mealtime habits of older people.

Reporting on interviews with 1894 people aged over 65 years about their diet and mealtime habits, (Huang, Cheng, Wahlqvist, Lo, & Lee, 2017) found that eating with others was beneficial and was associated with: being able to participate more in mealtime routines, having higher physical functioning, a better diet quality, and lower risk of death. Further, quality of life is significantly affected by dysphagia-related changes in mealtimes for people with amyotrophic lateral sclerosis (ALS) (Paris et al., 2013), Parkinson's Disease (Plowman-Prine et al., 2009) and head and neck cancer (Nund et al., 2014). Adults with ALS and oropharyngeal dysphagia had significantly lower self-reported quality of life, specifically in relation to their social life (Paris et al., 2013).

However, quality of life measures did not always correspond with the identification of impairments in mealtime and social participation. In individuals with dysphagia following total laryngectomy, the WHOQoL-Bref did not identify significant differences in quality of life compared to those with no dysphagia. However, the UW-QoL measure did identify that the same group of people with dysphagia had significantly lower scores on the social scale indicating self-reported problems with anxiety, pain, mood, activity and recreation (Maclean, Cotton, & Perry, 2009).

As such, it appears that regardless of whether the dysphagia, coughing, and choking is of a lifelong or acquired origin, people with disability and dysphagia experience embarrassment and social isolation related to their difficulties with meals. There is little information in the literature about how speech pathologists or other health professionals manage these impacts of dysphagia, and the stories of experience reflect that people with disability and dysphagia adopt their own strategies, which include avoidance of the situation, and a tendency to avoid the recommended modifications which are not socially accepted (e.g., taking more time to eat; eating puree food that does not look like the usual food).

The small amount of research on the problem to date indicates that swallowing difficulties can lead to limitations or restrictions in participation in mealtime activities, and this can impact negatively on the person's quality of life. To date, there is very little information regarding how to intervene on either the person's dysphagia impairment or their activity or participation restrictions, to prevent these negative impacts on quality of life and wellbeing.

Health and Quality of Life in Relation to Dysphagia

The health impacts of dysphagia are widely reported and can be serious, long-lasting, and substantial (Blisard et al., 1988; Chadwick & Jolliffe, 2009; Finestone, Fisher, Greene-Finestone, Teasell, & Craig, 1998; Goh et al., 2016; Guthrie & Stansfield, 2017; Hughes, Enderby, & Hewer, 1994; Morad, Kandel, & Merrick, 2009). These impacts are amplified for people who have a higher prevalence of dysphagia, including those with lifelong health conditions or disabilities (Robertson, Chadwick, Baines, Emerson, & Hatton, 2017), and people with acquired health conditions or disabilities (Ho, Liu, & Huang, 2014). At the level of body structure and functions associated with dysphagia, there is a substantial body of knowledge on assessment (Sheppard, Hochman, & Baer, 2014; Sheppard et al., 2017; Yilmaz, Basar, & Gisell, 2004) and interventions (Bath, Bath-Hextall, & Smithard, 2008; Morgan, Dodrill, & Ward, 2012; Speyer, Baijens, Heijnen, & Zwijnenberg, 2010) which guides clinicians in identifying and treating swallowing impairments to mitigate against the effects of dysphagia on health.

Given their relatedness, mealtime participation (as affecting quality of life), and the safety of food and drink consumption (as affecting airway protection and respiratory and nutritional health) must both be considered in any ethical decision-making framework applied in relation to dysphagia and mealtime management. Speech pathologists and others face ethical dilemmas in balancing the safety aspects of dysphagia management with any conflicting priorities in a person's own preferences and needs for mealtime participation (Kenny, 2015). In an illustrative case study, Kenny (2015) highlighted the need for speech pathologists to consider patient preferences and quality of life when making recommendations and diet modifications to manage dysphagia and minimise the risk of choking and aspiration. To achieve the best outcomes, Balandin and colleagues (2009) argued that "the involvement of all stakeholders is more likely to ensure that the adults with cerebral palsy have their needs and preferences met, and that the mealtime environment is safe and enjoyable" (p.203).

AIM

The initial aim of this review was to identify speech pathology research investigating or reporting on (a) the impact of dysphagia or feeding difficulties on a person's participation or inclusion, or (b) the impact of interventions for dysphagia or feeding difficulties on a person's mealtime participation or inclusion. Ultimately, this aim was broadened to include other disciplines and more broadly related interventions.

METHOD

In April 2018, 5 scientific databases (CINAHL Complete, EMBASE, MEDLINE, PsycINFO, Web of Science) and Google Scholar were searched to identify any peer-reviewed research (conference paper or journal article) reporting on interventions to improve participation and quality of life in people with chronic or lifelong dysphagia. The search was limited to studies written in English. Because of the need for information relevant to people eligible for the National Disability Insurance Scheme funding, search terms relating to disability were included in the search. A broad definition of 'participation' and 'inclusion' was applied, being any information relating to the person with dysphagia taking any part in any aspect of food/drink acquisition, preparation, eating/drinking, mealtime cultural routines; and included any measures of 'quality of life' (health-related or socially related or otherwise). That is, participation, inclusion, and quality of life were conflated as all being relevant to this review.

Search Stage 1: Dysphagia, mealtimes, disability, speech pathology

Because of the important role of speech pathologists/speech language therapists in the management of dysphagia in Australia, terms relating to this profession were included to identify potentially relevant literature. Search terms used were various permutations and combinations of terms relating to: (i) Dysphagia (including swallowing, deglutition, eating, feeding, swallowing therapy, swallowing impairment, deglutition disorders, eating disorders) *and* Mealtime (including meals, eating, feeding); (ii) Disability (including International Classification of Function Disability and Health; ICF, intellectual disability, disabled, disabled persons, developmental disability); (iii) Intervention (including early intervention, therapy, therapeutics); (iv) Participation and inclusion (including patient participation, social participation, community participation, activity and participation, inclusion, social inclusion, quality of life); and (v) Speech pathology (including speech-language pathology, speech therapy, speech-language therapy).

This search yielded a total of 1105 potentially relevant studies (including original research, reviews and discussion papers). LB screened all records first on a reading of each title to identify potentially relevant papers and excluded all irrelevant studies ($n = 1037$) not relating to disability dysphagia, mealtimes, interventions, and inclusion/participation/quality of life. LB then examined the 'title and abstract' of 68 records and excluded 29 that: (a) not relate to outcomes for people with disability and (chronic or lifelong) dysphagia but to the therapist or carer ($n = 15$); (b) did not report any dysphagia interventions ($n = 5$) (2 studies examine the association between dysphagia and cognitive impairment, a literature review didn't identify any studies reporting dysphagia interventions, and 2 looked at mealtime behaviours without intervention); or (c) did not examine any element of participation or inclusion in relation to meals ($n = 9$). Full texts of the remaining 39 papers were retrieved for further evaluation. Of these, a further 33 were excluded that (a) did not examine participation ($n = 10$); (b) were conference abstracts with no full text available ($n = 9$); (c) did not examine outcomes of people with dysphagia ($n = 6$); (d) reported the assessment and classification of dysphagia using the ICF and not interventions ($n = 6$); (e) was a protocol paper ($n = 1$); and (f) did not report a speech pathology intervention ($n = 1$ paper; a mealtime intervention from nursing and preventative medicine). Thus, 6 studies remained in the review: 2 systematic reviews examining the participation outcomes of dysphagia interventions (Jones et al., 2018; Morgan et al., 2012); 3 intervention studies (Argolo, Sampaio, Pinho, Melo, & Nobrega, 2013; Brunner, Skeat, & Morris, 2008; John, Enderby, & Hughes, 2005); and 1 composite case report (Kenny, 2015). See Figure 1 for a PRISMA summary of the search process.

Search Stage 2: Feeding, Autism Spectrum Disorders, speech pathology

The American Speech-Language and Hearing Association (ASHA) use the term 'feeding impairments' to refer to a narrower range of impairments in the oral phase of swallowing (American Speech-Language-Hearing Association, n.d.). Feeding difficulties and associated problematic mealtime behaviours are

reportedly common in children with Autism Spectrum Disorder (ASD) (Marshall, Hill, & Dodrill, 2013). Problematic mealtime behaviours may include fussy eating, also called faddy, choosy, picky or finicky eating: “unwillingness to eat familiar foods or try new foods, severe enough to interfere with daily routines to an extent that is problematic to the parent, child, or parent-child relationship” (Taylor, Wernimont, Northstone, & Emmett, 2015, p. 352); or food neophobia: “reluctance to eat or avoidance of new foods” (Taylor et al., 2015, p. 350). These problematic feeding behaviours may arise as a result of oral sensitivities (Twachtman-Reilly, Amaral, & Zebrowski, 2008) or ritualistic behaviours often associated with ASD (Marshall et al., 2013).

Given the paucity of evidence located in Search Stage 1, in this stage additional search terms were used in various permutations and combinations to identify any studies relating to speech pathology interventions for ‘feeding impairments’ as described previously, particularly ‘oral sensitivity’ or ‘fussy eating’ in people with ASD: (i) speech pathology (including speech-language pathology, speech therapy, speech-language therapy); (ii) oral Sensitivity (fussy/faddy/choosy/picky/finicky eating, feeding behaviour, food preferences, feeding and eating disorders of childhood, eating); and (iii) Autism Spectrum Disorder (including Autism, ASD, Autistic disorders, Asperger’s). This search located 52 potentially relevant papers. LB screened these by reading titles and excluded irrelevant papers ($n = 42$) and retained 10 papers for further examination of ‘title and abstract’ and excluded 9 that did not relate to interventions or outcomes for people with ASD. The full text of the remaining paper was retrieved for further evaluation. An additional 7 records were retrieved through a targeted search of ASD and feeding interventions. The full text of the remaining 8 papers were examined and 6 studies were excluded as these (a) did not report on participation or inclusion ($n = 5$), or (b) did not report the outcomes of feeding interventions, only the process of intervention ($n = 1$). Thus, only two studies remained in the review - an intervention study that included anecdotal reports of participation and inclusion following an intervention for three children with ASD (Muldoon & Cosbey, 2018), and a narrative review of mealtime interventions (Twachtman-Reilly et al., 2008). See Figure 2 for a PRISMA summary of the search process and outcomes.

Search Stage 3: Dysphagia, mealtimes, disability in any field

The search of all databases was repeated using the same terms for dysphagia, disability, intervention and participation, without restriction to speech pathology, to identify any dysphagia or feeding interventions implemented in other disciplines, including occupational therapy, physiotherapy, education and psychology. This search yielded a total of 3422 potentially relevant studies (including original research, reviews and discussion papers) which included the single article found in the prior search (which ultimately came to be excluded at this stage). LB examined the ‘title and abstract’ of 2692 records after duplicates were removed and excluded 2655 that: (a) were not peer reviewed ($n = 212$), (b) were not written in English ($n = 149$), (c) Were abstracts only with no full texts available ($n = 16$), (d) did not relate to dysphagia, eating or feeding ($n = 1701$), (e) did not report any interventions ($n = 307$), (f) addressed eating disorders or nutrition only, not dysphagia, eating or feeding ($n = 209$), and (g) did not examine any element of participation or inclusion in relation to meals ($n = 61$). Full texts of the remaining 37 papers were retrieved for further evaluation. Of these, a further 36 were excluded that: (a) did not examine participation ($n = 6$), (b) were conference abstracts with no full text available ($n = 8$), (c) did not examine outcomes of people with dysphagia ($n = 2$), (d) reported the assessment of dysphagia, but no intervention ($n = 9$), (e) examined outcomes related to PEG or tube feeding only ($n = 10$), (f) reported a speech pathology intervention that was included in search Stage 1 ($n = 1$). Thus, only one study remained to be added to the review: a single case design study mealtime intervention targeting food selectivity in a child with ASD, from the discipline of education (Binnendyk & Lucyshyn, 2009). See Figure 3 for a PRISMA summary of the search process.

Search Stage 4: Citation ancestry search

The combination of the 3 search stages (dysphagia + feeding impairments + across disciplines) identified 9 studies for inclusion in this review. Forward and back citations for these studies yielded an additional 11 relevant studies reporting (a) dysphagia interventions in speech pathology with participation, inclusion or quality of life outcomes ($n = 6$); (b) speech pathology interventions for mealtimes and feeding for children with Autism, with participation, inclusion or quality of life outcomes ($n = 1$), and (c) interventions in other fields with participation, inclusion or quality of life outcomes ($n = 5$). Disciplines of research included education, nursing, and occupational therapy; three studies addressed dysphagia or mealtime interventions, and two studies reported feeding interventions for children with ASD.

RESULTS

Dysphagia Interventions and Mealtime Participation

Using broad search terms and definitions, with no limits on date, we located 14 studies that included any relevant outcomes on participation, inclusion or quality of life outcomes of dysphagia interventions. The relevant findings were found in 3 systematic reviews, 10 intervention studies (including 3 RCTs), and 1 ‘composite case study’. Overall, 12 of the 14 studies examined interventions delivered by speech pathologists, 1 reported a study involving occupational therapists, and 1 reported a study involving a multidisciplinary team ($n = 1$). These studies and relevant findings are presented in Table 1.

Interventions for Fussy Eaters/Oral sensitivities/feeding impairment

We located six studies reporting participation, inclusion, or QoL outcomes following interventions for ‘fussy eating’ or ‘oral sensitivity’ in children with ASD. Three of these studies reported on interventions delivered by speech pathologists, and three reported on behavioural interventions delivered by educators. The reports included one systematic review, one narrative review, and four intervention studies (including 3 single case reports). In five of the six studies, qualitative research methods were used to assess the impact of the intervention on participation inclusion, or quality of life. In the remaining study, the Resident Lifestyle Inventory (RLI) was used to measure participation in conjunction with parental reports (Lucyshyn et al., 2007). Three studies examined participation, inclusion and/or quality of life outcomes for children with ASD after educators had implemented Positive Behaviour Supports. The findings of these studies suggest that mealtime interventions could improve participation in mealtime activities, and in family life more generally for children with ASD, and that this participation could have positive implications for a family’s quality of life. These studies and relevant findings are presented in Table 2.

Interventions Targeting the Mealtime Environment

Only one study was found which related to adults with dementia who required assistance with feeding (Van Ort & Phillips, 1995). Further to this one, in searching for studies about dysphagia, we located four other studies reporting interventions for older adults living in aged care settings, a population at high risk of dysphagia or eating impairments (Altus, Engelman, and Mathews (2002); Davies and Snaith (1980); Van Ort and Phillips (1995); VanBiervliet, Spangler, and Marshall (1981); Vucea, Keller, and Ducak (2014)). While these studies did not report on presence or absence of dysphagia, they reported participation and inclusion outcomes following interventions aimed to improve the mealtime environment. Four studies were from the discipline of nursing and one was from psychology. Four of the five studies were intervention studies that used qualitative observational methods and compared behaviours between standard mealtime and intervention conditions. One study reported a scoping review of mealtime interventions for adults in long term care facilities. These studies suggested that interventions that changed the environment in which meals were served, and the method of food delivery in a dining room, could lead to greater participation in mealtime routines and social interaction amongst long term care residents. These studies and relevant findings are presented in Table 3.

Summary

A broad literature search for evidence of speech pathology interventions to improve participation and quality of life in people with chronic or lifelong dysphagia found little relevant evidence. Several studies suggested that interventions that reduced the severity of dysphagia also had positive impacts on quality of life (Brunner et al., 2008; John et al., 2005; Jones et al., 2018; Skeat & Perry, 2005). However, bolus modification was one intervention that appeared to have negative effects on participation, inclusion and quality of life for people with dysphagia (Kenny, 2015; Swan, Speyer, Heijnen, Wagg, & Cordier, 2015). Interventions targeting mealtime environments in aged care settings show some positive effects on participation and inclusion for older residents. In the more specific area of interventions targeting oral sensitivity and feeding difficulties in children with ASD, six studies reported positive participation outcomes in stories of experience. Further research is needed to investigate the impact of dysphagia on participation and inclusion in individuals with disability and dysphagia or feeding impairments, and the effects of dysphagia interventions on mealtime participation or inclusion.

CONCLUSION

To date, research in the field of dysphagia and its impacts on quality of life, wellbeing, and participation or inclusion is limited. Studies examining quality of life primarily adopt a quantitative paradigm or approach, frequently involving measures of ‘quality of life’ and ‘swallowing related quality of life’ in standardised tools designed for people with stroke. While there is evidence supporting the view that dysphagia impacts negatively on quality of life and participation, there is little information available about whether interventions aimed at improving dysphagia-related outcomes impact on outcomes related to quality of life, participation, or inclusion. These concepts are rarely considered or explored in detail in the dysphagia literature.

While there is some evidence on the effects of dysphagia and mealtime interventions on quality of life, participation and inclusion outcomes were not often reported in studies of dysphagia or mealtime interventions. The qualitative aspects of the living with dysphagia for individuals with lifelong or acquired dysphagia need further research to explore a wide range of concepts related to participation and inclusion. It is also important to develop an in-depth understanding of factors that might be amenable to change in the mealtime environment which impact positively on a person’s mealtime-related participation and inclusion.

More research, particularly based on stories of experience of people with disability and dysphagia, is needed to determine: (a) the nature and extent of the impact of lifelong or chronic dysphagia on mealtime participation and inclusion, (b) the impact of dysphagia interventions on participation and inclusion, and (c) whether dysphagia/feeding interventions are effective in increasing mealtime participation and inclusion, and participation and inclusion more broadly (i.e., beyond mealtimes into other activities). It is important to challenge the assumption that measuring quality of life is an adequate reflection of a person’s mealtime-related participation and inclusion, and to properly conceptualise each of these domains for individuals with disability and dysphagia prior to attempts to measure outcomes related to these domains.

Authors: Lucy Bryant and Bronwyn Hemsley

Location: The University of Technology Sydney 30th June 2018

Contact Author:

Bronwyn Hemsley, Ph.D.

Professor of Speech Pathology, Head of Discipline

Bronwyn.Hemsley@uts.edu.au

@BronwynHemsley

Table 1. Studies included in the review: Dysphagia interventions

Study	Quality and Level of Evidence (NHMRC)*	Description	Relevant Finding
Jones et al. (2018)	Level IV (intervention) Systematic review of level III-1 (n=4) and IV (n=31) evidence	Systematic review of relationships between health-related quality of life (HRQoL) and oropharyngeal dysphagia, and changes in dysphagia and HRQoL following intervention. A range of interventions were identified across the 35 included studies.	Most of the included studies identified an inverse relationship between dysphagia and HRQoL, meaning HRQoL improved as dysphagia severity reduced. In some studies, this relationship was significant. This review supported the findings of individual studies showing that after successful treatment for dysphagia, HRQoL improved.
Brunner et al. (2008)	Level III-3 (intervention) A comparative intervention study with pre-test/post-test outcomes, without concurrent controls	Intervention study using a two-group repeated measures design; Authors examined the outcomes of speech pathology rehabilitation following stroke for 63 stroke patients over a 12-month period. Participants received “usual care” for communication and swallowing, and specific intervention techniques were not documented.	Results indicated “ <i>a trend towards increasing outcome scores with increasing SLP input for the patients seen in this study in relation to swallowing difficulties, and to the Participation and Distress/ Wellbeing domains</i> ” (p.311) of the AusTOMs. These results suggest that swallowing rehabilitation may have a positive impact on participation for adults with ongoing dysphagia following stroke.
John et al. (2005)	Level III-3 (intervention) A longitudinal cohort intervention study without controls	Longitudinal cohort study; examined outcomes of “speech and language therapy for services for individuals with dysphagia” (p. 167), for 142 patients accessing 8 Australian therapy services for treatment of dysphagia. Specific intervention techniques were not identified.	Following speech and language therapy services, 74% of people with dysphagia reported positive changes in participation, 24% sustained original level of participation, and 2.1% showed negative changes, as measured using the AusTOMs. These results suggest that speech and language therapy interventions may have positive effects of participation for some adults with dysphagia.
Skeat and Perry (2005)	Level IV (diagnostic) Study of diagnostic yield with no reference standard	This study aimed to examine the AusTOMs swallowing scale. Data from the scale was collected from 56 speech pathologists, reporting on 183 episodes of client care. As in the studies by Brunner et al. (2008) and John et al. (2005), the nature of the interventions used to treat dysphagia were not identified. The authors included findings on QoL and participation outcomes in their report.	From pre- to post-intervention, 60% of patients reported improvement on the impairment and activity domains, 48% identified improvements in participation, and 42% reported improved well-being. Few participants showed deterioration on any of the scales. It should be noted that the magnitude of these changes was not documented, however outcomes suggested that, in most cases, dysphagia intervention would affect positive changes on impairment, activity, participation and/or well-being.
Chadwick et al. (2003)	Level III-3 (intervention) Observational cohort study without control	Observational study; examined adherence to mealtime guidelines or plans by 40 adults with intellectual disability and dysphagia included incidental comments that suggested the impacts of mealtime modifications on participation and inclusion.	The authors found that participants showed greater adherence to guidelines for food and drink consistency, positioning and utensil use. Guidelines that related to support, prompting and socialising during meals were more likely to be ignored. Indeed, the authors reported that “ <i>when people with intellectual disabilities were able to feed themselves, caregivers seldom supported, prompted, or socialized with the individual, even if these behaviors were recommended in the guidelines.</i> ” (p. 207-208) and suggested that this might be because “ <i>A number of the more cognitively able people often objected to being watched or prompted or to having the consistency of their food altered.</i> ” (p. 208).
Morgan, Dodrill, and Ward (2012)	Level I (intervention) Systematic Review of RCTs	Systematic review of dysphagia interventions for children with neurological impairments; included 3 studies all reporting indirect interventions targeting physiological limitations in oropharyngeal dysphagia. Data regarding nutritional, respiratory and participation implications were extracted from all studies.	The included studies did not report any outcomes related to the “ <i>child’s level of participation in mealtime routine with family, peers or strangers</i> ” (Morgan et al., 2012, p. 15).
Argolo et al. (2013)	Level III-3 (intervention)	An intervention study using a pre/post repeated measures design for 15 adults with Parkinson’s disease in Brazil, using Oral Motor Exercises to target	Following the intervention, participants showed no significant improvements overall; however, subscales of fear and symptom

	A comparative intervention study with pre-test/post-test outcomes, without concurrent controls	swallowing function and related quality of life. Quality of life outcomes were measured using the SWAL-QOL.	frequency also significantly improved. The authors noted that changes in these QoL subscales had no correlation with changes in swallowing function.
Swan et al. (2015).	Level III-2 (intervention) Systematic review of RCTs (n=1) and non-randomised clinical trials (n=7)	Systematic review; examining the effect of bolus modification on HRQoL	Greater levels of modification were generally associated with more impaired QoL. Additionally, food modifications may have had greater impact than fluid modifications.
Kenny (2015)	Unclassifiable** 'Composite case study' Single descriptive case study	'Composite case study'; illustrated the negative effects that dysphagia management could have on mealtime participation, using the example of a 68-year-old man with dysphagia following a stroke. In this case, a texture-modified diet of puréed food and thickened fluids was prescribed to minimise the risk of aspiration associated with severe oral and pharyngeal dysphagia.	The man refused to accept texture-modified food in the presence of friends and family. Kenny reported that " <i>He indicated that sharing a 'normal' meal was integral to personal satisfaction and maintaining his social relationships</i> " (p.649). As such, dysphagia management had to strike an ethical balance between education, minimising medical risk to him, and ensuring his quality of life was not impaired.
Stegemoller et al. (2017)	Level III-3 (intervention) A comparative intervention study with pre-test/post-test outcomes, without concurrent controls	Cohort intervention study of 'therapeutic singing' as an intervention to treat 'swallowing' in 24 adults with Parkinson's disease and no significant dysphagia symptoms. Two groups of participants received the intervention, one at high intensity and one at low intensity. QoL was measured using the SWAL-QOL.	No effect on QoL.
Lin et al. (2011)	Level II (intervention) Randomised Control Trial	Compared functional electrical stimulation (FES) using VitalStim to treat dysphagia to a 'standard' home rehabilitation program for 20 adults with nasopharyngeal carcinoma. All participants had been treated with radiotherapy a year prior to the study, and had dysphagia as identified using the Dysphagia Outcome and Severity Scale (DSS). At pre- and post-intervention, QoL was assessed using the MDADI.	No significant changes were observed for the group receiving the home rehabilitation program.
Heijnen, Speyer, Baijens, and Bogaardt (2012)	Level II (intervention) Randomised Control Trial	Used NMES to treat dysphagia, in 88 adults with Parkinson's disease and oropharyngeal dysphagia. Compared (1) Traditional therapy using oral muscular exercises, (2) traditional therapy supplemented with NMES motor stimulation, and (3) traditional therapy supplemented with NMES sensory stimulation. In all groups, health related QoL was measured using the SWAL-QOL and the MDADI.	Significant improvements were seen for the total participant group on the SWAL-QOL symptom index and burden scale, and for the global, physical and emotional subscales of the MDADI. The traditional therapy group also reported improvements on the SWAL-QOL symptom index and MDADI global assessment score. The NMES-motor group showed significant changes on the MDADI total score. No other significant changes in scores on the SWAL-QOL or MDADI were reported. These results suggested negligible effect of NMES intervention on QoL for people with dysphagia.
Zhang et al. (2016)	Level II (intervention) Randomised Control Trial	Compared NMES with the 'traditional' therapy of " <i>postural adjustment or diet modification, increasing the sensory input through thermal-tactile stimulation, strengthening weak oropharyngeal musculature through oral exercise, swallowing manoeuvres</i> " (p. 357); involved 82 adults with dysphagia following a medullary infarct. In this study, QoL outcomes were measured using the SWAL-QOL.	Reported that all groups showed significant improvements in overall QoL.
Rogus-Pulia et al. (2016)	Level III-3 (intervention) A comparative intervention study with pre-test/post-test outcomes, without concurrent controls	Cohort intervention study; examined a multidisciplinary intervention program for people with dysphagia, the Swallow STRENGTHENING OropharyNGeal (Swallow STRONG) program; along with participation, inclusion and/or quality of life outcomes. Participants were 56 older adult veterans with dysphagia associated with cancer, laryngectomy, motor neurone disease, Parkinson's disease and dementia.	A comparison of QoL outcomes, measured using the SWAL-QOL, from pre- to post-intervention showed improvements on all subscales. These changes were significant for eating desire, physical, food, communication, fear, mental health, social, and fatigue. These results suggested wide-ranging improvements in QoL following multidisciplinary treatment of dysphagia.

* Level I studies represent the highest level of evidence. Higher numbers represent less rigorous levels of evidence

** Unclassifiable studies do not contain sufficient evidence to meet the minimum standard for NHMRC levels of evidence

Table 2. Studies included in the review: Interventions for Fussy Eaters/Oral Sensitivities

Study	Quality and Level of Evidence	Intervention for Fussy Eaters/Oral Sensitivities	Relevant Finding
Muldoon and Cosbey (2018)	Level IV (intervention) Case series with pre-test/post-test outcomes	Reported the follow-up results of a train-the-trainer model delivering the EAT-UP (Easing Anxiety Together with Understanding and Perseverance) feeding intervention. The study measured changes in difficult mealtime behaviours for three children and their families following the intervention.	Results showed positive effects on mealtime behaviours. Additionally, parental reports supported these changes by reflecting the impacts on mealtime participation and inclusion. One mother noted <i>“meaningful differences in her ability to manage [her son’s] behaviour, in his ability to eat independently, and in the variety of food that he accepted at mealtimes. She was no longer observed to feed him forcibly from behind and reported that he ate independently at home and in restaurants”</i> (Muldoon & Cosbey, 2018, p. 283).
Gosa et al. (2017)	Level IV (intervention) Systematic review of primarily level IV evidence	A systematic review by Gosa, Carden, Jacks, Threadgill, and Sidlovsky (2017) identified and summarised findings from 61 relevant studies that examined outcomes of feeding interventions in children, including oral motor, sensory-based, behavioural-based, and pharmaceutical-based interventions.	Of the 37 identified studies that implemented behavioural interventions, the authors only identified one case where the intervention led to reported improvements in <i>“parent-child interactions during mealtimes”</i> (Gosa et al., 2017, p. 125).
Cheremshynski et al. (2013)	Unclassifiable Single descriptive case study	Used positive behaviour support to improve food selectivity in a 5-year-old boy with ASD.	Results from qualitative interview with mother following the intervention indicated that the child had improved participation in family mealtimes following the intervention. The mother reported <i>“When I was little, the whole family would eat together. Now, I’m glad he joins in. It is nice.”</i> (Cheremshynski et al., 2013, p. 249).
Binnendyk and Lucyshyn (2009)	Unclassifiable Single descriptive case study	A single case study intervention targeting food selectivity in a child with Autism. The intervention used Positive Behaviour Support strategies, to introduce new foods and encourage positive feeding behaviours around self-feeding and table manners. Quality of life outcomes were measured using Likert scales and qualitative data from parental report	The authors noted that: <i>“teaching Karim to sit at the table, feed himself using a utensil, and put his dishes away appeared to change his mother’s perception of him as a child who needed constant support to one who could be taught to be more independent. Given this change in perception, the mother began to assign Karim other responsibilities, such as dressing himself in the morning and putting his shoes and coat away after school.”</i> (p.59)
Twachtman-Reilly et al. (2008).	Unclassifiable Narrative literature review only	A narrative review of literature addressing feeding disorders in children with ASD in school-based settings also provided a story of experience that illustrated the promotion of participation through an intervention to manage behaviourally-based feeding issues.	When discussing the pace of therapy, the authors noted a case of a child who demonstrated a clear preference for crunchy foods. The intervention was paced to provide the child with choice and control over trialling new foods. As a result, <i>“this student was gradually able to join with his peers in this activity when they all were given the option of putting crunchy sprinkles in their respective pudding cups”</i> (p.268). While the authors did not link this story of experience to the concept of mealtime participation, the story nonetheless demonstrates an instance where this was considered in a feeding intervention.
Lucyshyn et al. (2007)	Unclassifiable Single descriptive case study	Used positive behaviour support to treat food selectivity and disruptive feeding behaviours in a single female with ASD and a diagnosis of moderate to severe intellectual disability. This longitudinal study commenced when the child was 5 years of age and concluded when she was 15. Participation in life and community activities was measured using the Resident Lifestyle Inventory and parental reports at 8 time points: once at pre-intervention, three times during the intervention (which lasted 2 years) and 5 times during the follow-up period (which lasted 7 years).	Community activity patterns improved during the intervention and were maintained with further improvement during the follow-up period. Additionally, eating out at a restaurant was identified as a preferred activity at follow-up. Improvements in participation were also evident in parental reports. The parents identified improvements in the child’s behaviour across the entire day, improved range and frequency of participation in community activities, less social isolation and fragmentation of family, and an increase in family activities. During follow-up, the mother stated: <i>“The end results have been wonderful, and by using the strategies and modifying them throughout the passage of time, our lives have blossomed and expanded in ways not thought possible before.”</i> and <i>“We now feel like we can do things together as a family, such as going to church together and going to friends’ homes for dinner.”</i> (p.144). One negative QoL outcome was noted for the sibling who identified that the increased attention received by the child with ASD during the intervention made her feel less important within the family unit.

* Level I studies represent the highest level of evidence. Higher numbers represent less rigorous levels of evidence

** Unclassifiable studies do not contain sufficient evidence to meet the minimum standard for NHMRC levels of evidence

Table 3. Studies included in the review: Interventions Targeting the Mealtime Environment for Older People in Aged Care

Study	Quality and Level of Evidence	Intervention Targeting the Mealtime Environment	Relevant Finding
Altus et al. (2002)	Unclassifiable Report of group outcomes with minimal interpretation and no control	Reported a mealtime intervention using an ABA design that examined mealtime participation under 2 different meal service conditions in a locked dementia ward. The 'usual' condition was an institution-style pre-prepared meal service. The intervention implemented a family-style meal condition where residents were served communal dishes and were required to serve their own food and pass dishes to other residents.	Prior to the intervention, participants were involved in approximately 10% of mealtime tasks, including preparation, serving and clean-up. During the intervention participation increased to 24% of tasks and returned to pre-intervention levels when the intervention was withdrawn. When the intervention was again implemented with addition of Positive Behaviour Support delivered by a trained nurse, participation increased to approximately 65% of tasks.
Davies and Snaith (1980)	Unclassifiable Report of group outcomes with minimal interpretation and no control	Examined an intervention that altered the mealtime environment on a geriatric ward of a continuing care hospital. All participants had varying degrees of disability, were in wheelchairs, and ate while seated in rows with their backs to the wall. The intervention changed service to seat participants at tables in groups of 6.	The changed mealtime arrangements led to a marked increase in social interactions between patients in both initiation and received interactions. Patient-to-patient assistance (such as helping with cutting of food and passing condiments) as well as communication between participants was observed to increase.
Van Ort and Phillips (1995)	Unclassifiable Report of group outcomes with minimal interpretation and no control	Examined the efficacy of two interventions – one contextual, one behavioural – to promote functional feeding and maintain adequate nutrition status in a population of older people with dementia living in a long-term care setting.	The contextual intervention minimised distractors, required meals to be eaten at the dining table, food was displayed in front of the participant, finger food was served at every meal and the meal started with finger food placed in hand of the participant, and functional role models were provided by seating participant between other residents that could feed themselves. Nursing guidelines were altered so that mealtimes were not disrupted. This intervention led to improved interaction with the carer assisting with feeding and with the food they were eating (e.g., touching food), less refusal, more consumption, and more self-feeding. The behavioural intervention implemented verbal and tactile prompts, role-modelling, cue synchronization and reinforcement to elicit functional feeding behaviours. This intervention led to more initiation of self-feeding, more refusal, more consumption, and more interaction with the person assisting.
VanBiervliet et al. (1981)	Unclassifiable Report of group outcomes with minimal interpretation and no control	Compared typical meal "institutional style serving procedures" where all individuals collected ready-prepared meals on a tray from carers, to a family style meal that involved the same procedure, except that residents collected serving bowls of food for the table, and residents passed and served own their meals. The intervention targeted five young adult males in a residential training centre for people with intellectual and developmental disability.	Results showed increased verbalisations during family style meals. This maintained well to follow-up. These changes appeared to occur specifically as a function of the mealtime procedure, and increased verbalisations were directed primarily at peers. For some participants at least, this was related to conversation rather than meal requests. The family-style meal condition was also associated with an almost twofold increase in time spent with the meal.
Vucea et al. (2014)	Level IV Systematic review of primarily level IV studies	A review of studies examining mealtime interventions for residents of long term care facilities. A systematic search strategy was used to identify 58 studies for inclusion.	Environmental interventions that altered the dining room space to a smaller, home-style meal environment appeared to have positive effects on mealtime communication, socialisation and quality of life. Interventions that changed the style of food service had no identified impact on quality of life, however may improve participation in mealtime routines. Interventions that targeted staff training and shared mealtimes increased autonomy, decreased wandering, improved frequency and quality of interactions and social interactions between residents.

* Level I studies represent the highest level of evidence. Higher numbers represent less rigorous levels of evidence

** Unclassifiable studies do not contain sufficient evidence to meet the minimum standard for NHMRC levels of evidence

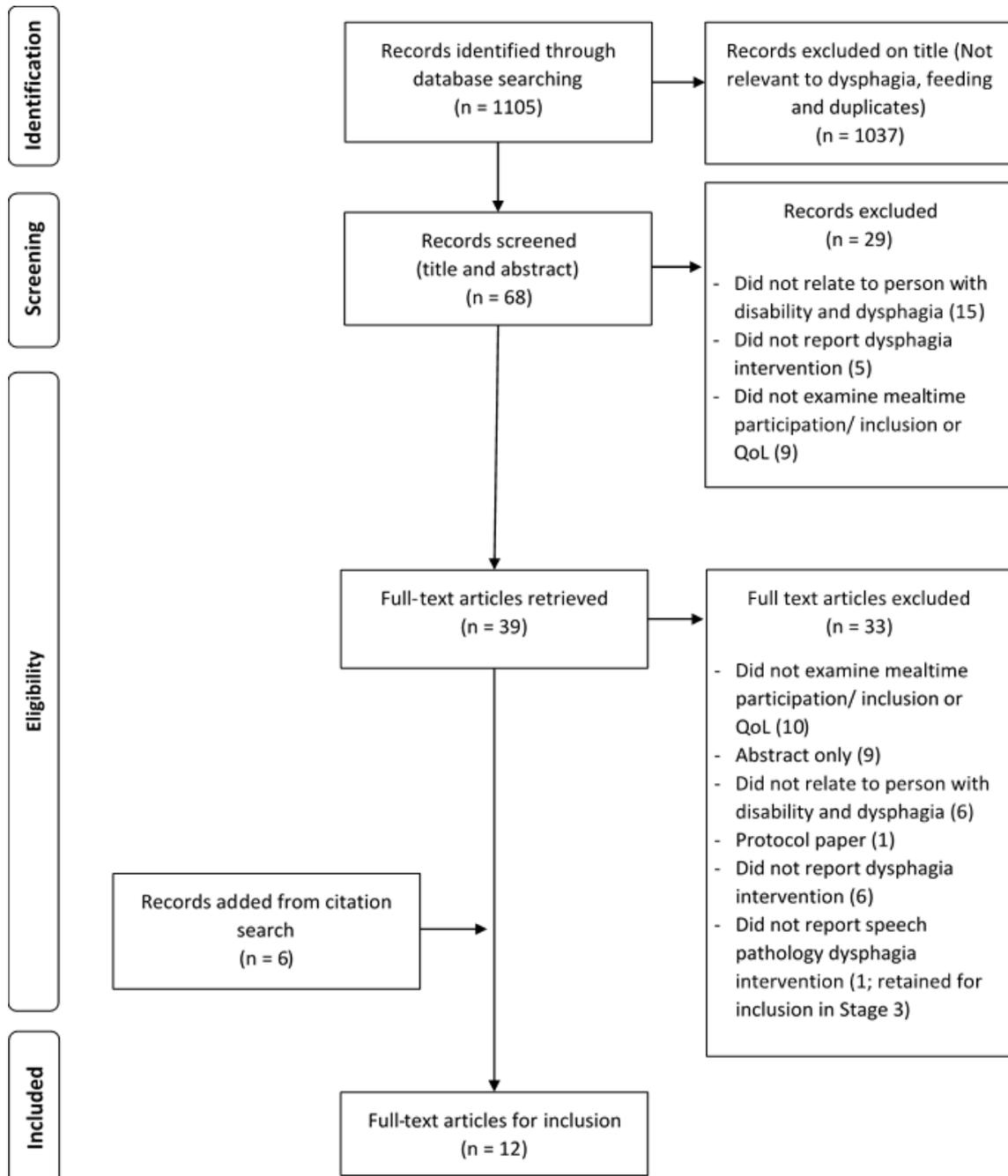


Figure 1: PRISMA Summary of search for Stage 1, speech pathology interventions for dysphagia

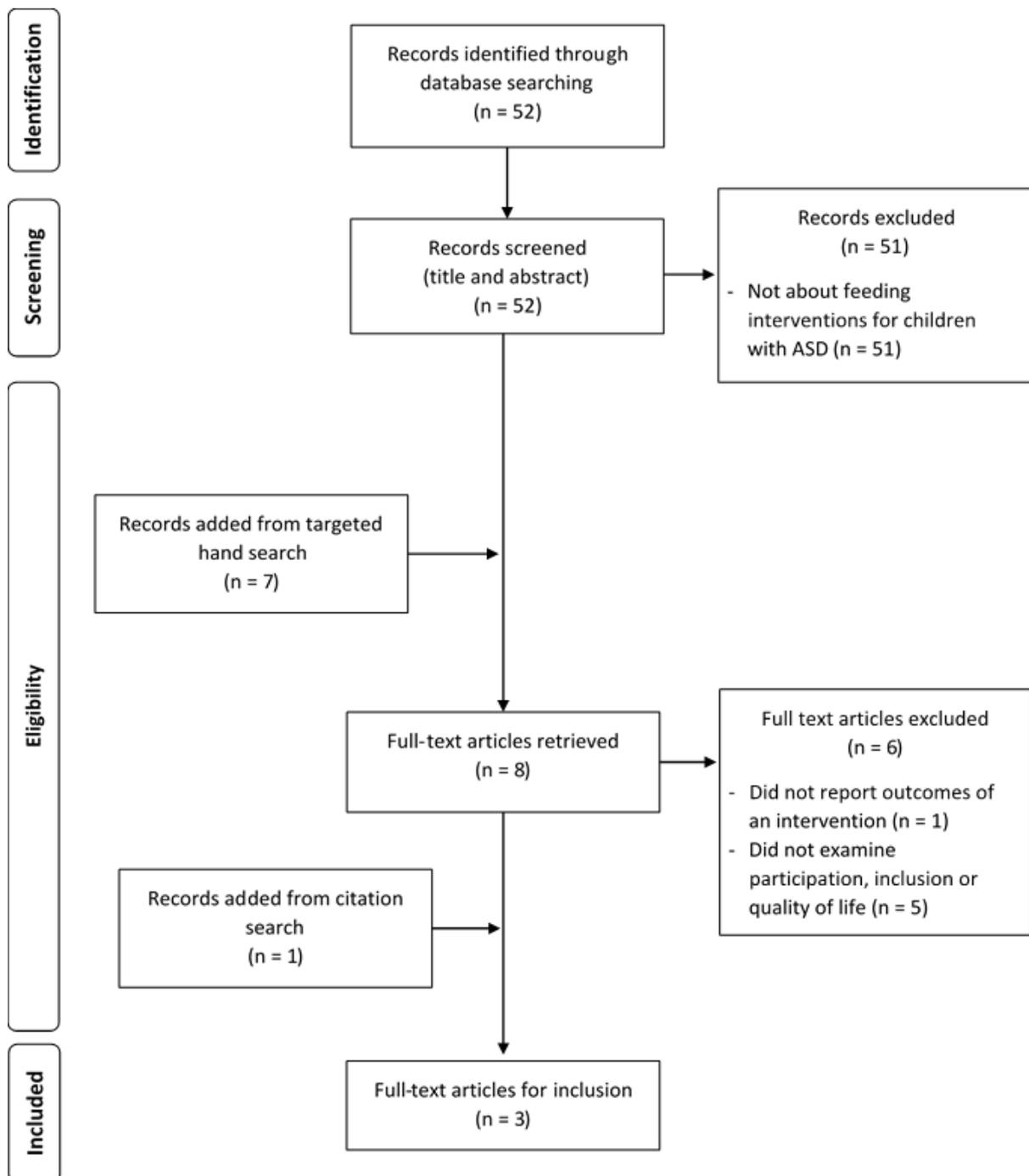


Figure 2: PRISMA Summary of search for Stage 2, speech pathology feeding interventions for children with ASD

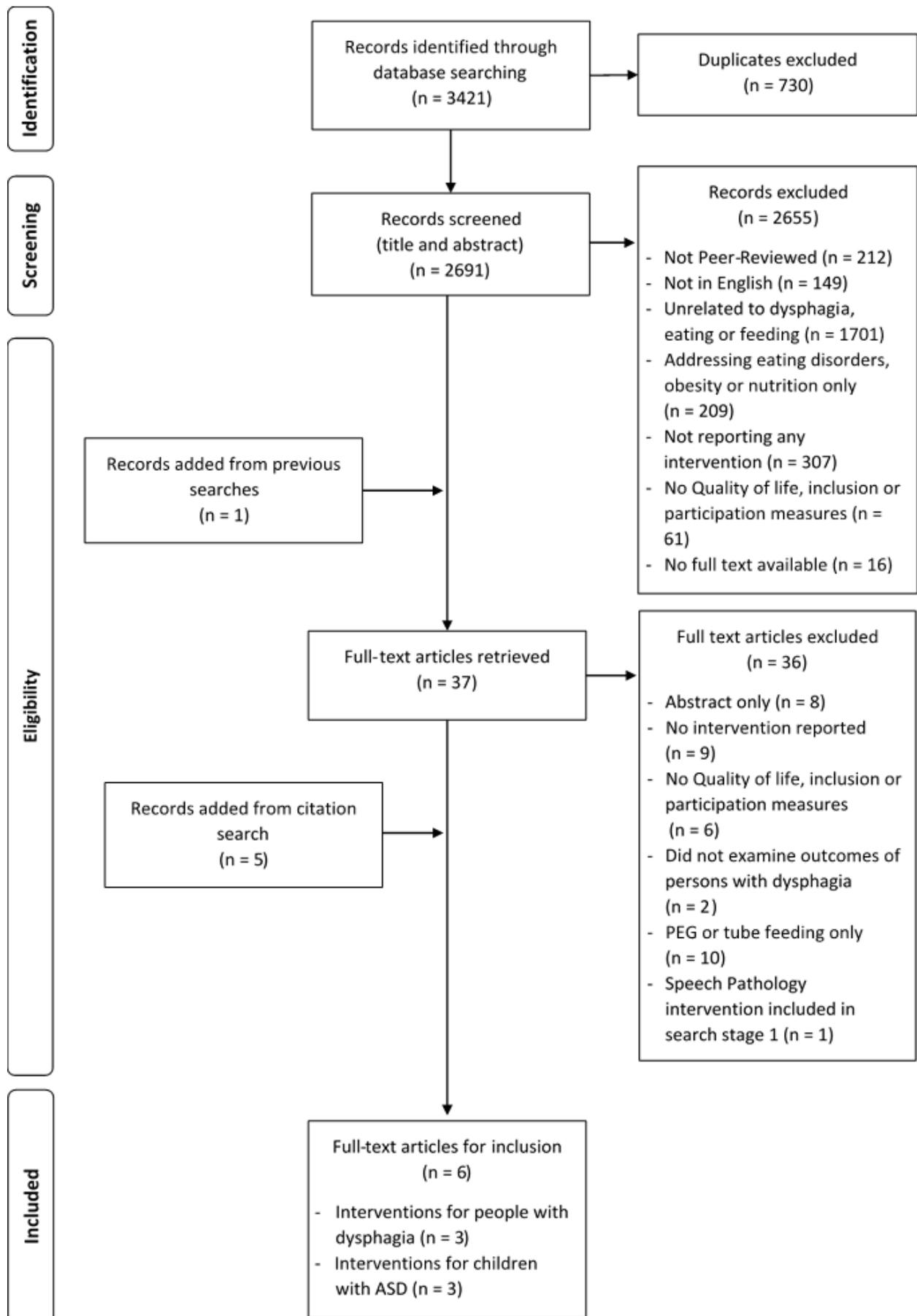


Figure 3: PRISMA Summary of search for Stage 3, all disciplines

References

- Altus, D. E., Engelman, K. K., & Mathews, R. M. (2002). Using family-style meals to increase participation and communication in persons with dementia. *Journal of Gerontological Nursing, 28*(9), 47-53.
- American Speech-Language-Hearing Association. (n.d.). Feeding and swallowing disorders in children. Retrieved from <https://www.asha.org/public/speech/swallowing/Feeding-and-Swallowing-Disorders-in-Children/>
- Argolo, N., Sampaio, M., Pinho, P., Melo, A., & Nobrega, A. C. (2013). Do swallowing exercises improve swallowing dynamic and quality of life in Parkinson's disease? *NeuroRehabilitation, 32*(4), 949-955. doi:<http://dx.doi.org/10.3233/NRE-130918>
- Balandin, S., Hemsley, B., Hanley, L., & Sheppard, J. J. (2009). Understanding mealtime changes for adults with cerebral palsy and the implications for support services. *Journal of Intellectual & Developmental Disability, 34*(3), 197-206. doi:10.1080/13668250903074489
- Bath, P. M. W., Bath-Hextall, F. J., & Smithard, D. G. (2008). Interventions for dysphagia in acute stroke. *Cochrane Library, 3*, 1-22.
- Binnendyk, L., & Lucyshyn, J. M. (2009). A Family-Centered Positive Behavior Support Approach to the Amelioration of Food Refusal Behavior An Empirical Case Study. *Journal of Positive Behavior Interventions, 11*(1), 47-62. doi:10.1177/1098300708318965
- Blisard, K. S., Martin, C., Brown, G. W., Smialek, J. E., Davis, L. E., & McFeeley, P. J. (1988). Causes of death of patients in an institution for the developmentally disabled. *Journal of Forensic Sciences, 33*(6), 1457-1462.
- Brunner, M., Skeat, J., & Morris, M. E. (2008). Outcomes of speech-language pathology following stroke: Investigation of inpatient rehabilitation and rehabilitation in the home programs. *International Journal of Speechlanguage Pathology, 10*(5), 305-313. doi:<https://dx.doi.org/10.1080/17549500802027392>
- Chadwick, D. D., & Jolliffe, J. (2009). A descriptive investigation of dysphagia in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(1), 29-43. doi:10.1111/j.1365-2788.2008.01115.x

- Chadwick, D. D., Jolliffe, J., & Goldbart, J. (2003). Adherence to eating and drinking guidelines for adults with intellectual disabilities and dysphagia. *Am J Ment Retard, 108*(3), 202-211. doi:10.1352/0895-8017(2003)108<0202:Ateadg>2.0.Co;2
- Cheremshynski, C., Lucyshyn, J. M., & Olson, D. L. (2013). Implementation of a culturally appropriate positive behavior support plan with a Japanese mother of a child with autism: An experimental and qualitative analysis. *Journal of Positive Behavior Interventions, 15*(4), 242. doi:<https://doi.org/10.1177/1098300712459904>
- Davies, A. D. M., & Snaith, P. A. (1980). The social behaviour of geriatric patients at mealtimes: An observational and an intervention study. *Age and Ageing, 9*(2), 93-99.
- Finestone, H. M., Fisher, J., Greene-Finestone, L. S., Teasell, R. W., & Craig, I. D. (1998). Sudden death in the dysphagic stroke patient--a case of airway obstruction caused by a food bolus: a brief report. *Am J Phys Med Rehabil, 77*(6), 550-552.
- Goh, K. H., Acharyya, S., Ng, S. Y. E., Boo, J. P. L., Kooi, A. H. J., Ng, H. L., . . . Tan, L. C. S. (2016). Risk and prognostic factors for pneumonia and choking amongst Parkinson's disease patients with dysphagia. *Parkinsonism & Related Disorders, 29*, 30-34. doi:10.1016/j.parkreldis.2016.05.034
- Gosa, M. M., Carden, H. T., Jacks, C. C., Threadgill, A. Y., & Sidlovsky, T. C. (2017). Evidence to support treatment options for children with swallowing and feeding disorders: A systematic review. *J Pediatr Rehabil Med, 10*(2), 107-136. doi:10.3233/prm-170436
- Guthrie, S., & Stansfield, J. (2017). Teatime Threats. Choking incidents at the evening meal. *Journal of Applied Research in Intellectual Disabilities, 30*(1), 47-60. doi:10.1111/jar.12218
- Heijnen, B. J., Speyer, R., Baijens, L. W., & Bogaardt, H. C. (2012). Neuromuscular electrical stimulation versus traditional therapy in patients with Parkinson's disease and oropharyngeal dysphagia: effects on quality of life. *Dysphagia, 27*(3), 336-345. doi:10.1007/s00455-011-9371-z
- Ho, Y.-H., Liu, H.-Y., & Huang, S.-T. (2014). The Prevalence and Signs of Dysphagia Among Stroke Patients in Rehabilitation Units. *Journal of Nursing, 61*(2), 54-62 59p. doi:10.6224/JN.61.2.54
- Huang, Y.-C., Cheng, H.-L., Wahlqvist, M. L., Lo, Y.-T. C., & Lee, M.-S. (2017). Gender differences in longevity in free-living older adults who eat-with-others: a prospective study in Taiwan. *BMJ Open, 7*(9), e016575. doi:<https://dx.doi.org/10.1136/bmjopen-2017-016575>

- Hughes, J. C., Enderby, P. M., & Hewer, R. L. (1994). Dysphagia and multiple sclerosis: a study and discussion of its nature and impact. *Clinical Rehabilitation*, 8(1), 18-26 19p.
- John, A., Enderby, P., & Hughes, A. (2005). Benchmarking outcomes in dysphasia using the Therapy Outcome Measure. *Aphasiology*, 19(2), 165-178.
- Jones, E., Speyer, R., Kertscher, B., Denman, D., Swan, K., & Cordier, R. (2018). Health-Related Quality of Life and Oropharyngeal Dysphagia: A Systematic Review. *Dysphagia*, 33(2), 141-172. doi:<http://dx.doi.org/10.1007/s00455-017-9844-9>
- Kenny, B. (2015). Food Culture, Preferences and Ethics in Dysphagia Management. *Bioethics*, 29(9), 646-652. doi:<https://dx.doi.org/10.1111/bioe.12189>
- Lin, P. H., Hsiao, T. Y., Chang, Y. C., Ting, L. L., Chen, W. S., Chen, S. C., & Wang, T. G. (2011). Effects of functional electrical stimulation on dysphagia caused by radiation therapy in patients with nasopharyngeal carcinoma. *Support Care Cancer*, 19(1), 91-99. doi:10.1007/s00520-009-0792-2
- Lucyshyn, J. M., Albin, R. W., Horner, R., Mann, J., Mann, J., & Wadsworth, G. (2007). Family implementation of positive behavior support with a child with autism: A longitudinal, single case experimental and descriptive replication and extension. *Journal of Positive Behavior Interventions*, 9, 131-150.
- Maclean, J., Cotton, S., & Perry, A. (2009). Dysphagia following total laryngectomy: The effect on quality of life, functioning and psychological well-being. *Dysphagia*, 24, 3140321. doi:10.1007/s00455-009-9209-0
- Marshall, J., Hill, R. J., & Dodrill, P. (2013). A survey of practice for clinicians working with children with autism spectrum disorders and feeding difficulties. *International Journal of Speechlanguage Pathology*, 15(3), 279-285. doi:10.3109/17549507.2013.777972
- McHorney, C. A., Robbins, J., Lomax, K., Rosenbek, J. C., Chignell, K., Kramer, A. E., & Bricker, D. E. (2002). The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III. Documentation of reliability and validity. *Dysphagia*, 17(2), 97-114. doi:10.1007/s00455-001-0109-1
- Morad, M., Kandel, I., & Merrick, J. (2009). Residential care centers for persons with intellectual disability in Israel: trends in mortality from food choking during 1991-2004. *Medical Science Monitor: International Medical Journal Of Experimental And Clinical Research*, 15(7), PH75-PH77.

- Morgan, A. T., Dodrill, P., & Ward, E. C. (2012). Interventions for oropharyngeal dysphagia in children with neurological impairment. *Cochrane Database of Systematic Reviews*, 10, CD009456. doi:<https://dx.doi.org/10.1002/14651858.CD009456.pub2>
- Muldoon, D., & Cosbey, J. (2018). A Family-Centered Feeding Intervention to Promote Food Acceptance and Decrease Challenging Behaviors in Children With ASD: Report of Follow-Up Data on a Train-the-Trainer Model Using EAT-UP. *American Journal of Speech-Language Pathology*, 27(1), 278-287. doi:10.1044/2017_AJSLP-17-0105
- Nund, R. L., Scarinci, N. A., Cartmill, B., Ward, E. C., Kuipers, P., & Porceddu, S. V. (2014). Application of the International Classification of Functioning, Disability and Health (ICF) to people with dysphagia following non-surgical head and neck cancer management. *Dysphagia*, 29(6), 692-703. doi:<https://dx.doi.org/10.1007/s00455-014-9563-4>
- O'Halloran, R., & Larkins, B. (2008). The ICF Activities and Participation related to speech-language pathology. *International Journal of Speech-Language Pathology*, 10(1/2), 18-26.
- Paris, G., Martinaud, O., Petit, A., Cuvelier, A., Hannequin, D., Roppeneck, P., & Verin, E. (2013). Oropharyngeal dysphagia in amyotrophic lateral sclerosis alters quality of life. *Journal of Oral Rehabilitation*, 40(3), 199-204. doi:10.1111/joor.12019
- Plowman-Prine, E. K., Sapienza, C. M., Okun, M. S., Pollock, S. L., Jacobson, C., Wu, S. S., & Rosenbek, J. C. (2009). The relationship between quality of life and swallowing in Parkinson's disease. *Movement Disorders*, 24(9), 1352-1358. doi:<https://dx.doi.org/10.1002/mds.22617>
- Robertson, J., Chadwick, D., Baines, S., Emerson, E., & Hatton, C. (2017). Prevalence of dysphagia in people with intellectual disability: a systematic review. *Intellectual and Developmental Disabilities*.
- Rogus-Pulia, N., Rusche, N., Hind, J. A., Zielinski, J., Gangnon, R., Safdar, N., & Robbins, J. (2016). Effects of Device-Facilitated Isometric Progressive Resistance Oropharyngeal Therapy on Swallowing and Health-Related Outcomes in Older Adults with Dysphagia. *J Am Geriatr Soc*, 64(2), 417-424. doi:10.1111/jgs.13933
- Sheppard, J. J., Hochman, R., & Baer, C. (2014). The Dysphagia Disorder Survey: Validation of an assessment for swallowing and feeding function in developmental disability. *Research in Developmental Disabilities*, 929-942.

- Sheppard, J. J., Malandraki, G. A., Hemsley, B., Troche, M., Balandin, S., Hochman, R., . . . Mishra, A. (2017). Validation of the Choking Risk Assessment and Pneumonia Risk Assessment for Adults with Intellectual and Developmental Disability (IDD). *Research in Developmental Disabilities, In 2nd Review*.
- Skeat, J., & Perry, A. (2005). Outcome measurement in dysphagia: not so hard to swallow. *Dysphagia, 20*(2), 113-122. doi:10.1007/s00455-004-0028-z
- Speyer, R., Baijens, L., Heijnen, M., & Zwijnenberg, I. (2010). Effects of therapy in oropharyngeal dysphagia by speech and language therapists: a systematic review. *Dysphagia, 25*(1), 40-65. doi:<https://dx.doi.org/10.1007/s00455-009-9239-7>
- Stegemoller, E. L., Hibbing, P., Radig, H., & Wingate, J. (2017). Therapeutic singing as an early intervention for swallowing in persons with Parkinson's disease. *Complement Ther Med, 31*, 127-133. doi:10.1016/j.ctim.2017.03.002
- Swan, K., Speyer, R., Heijnen, B. J., Wagg, B., & Cordier, R. (2015). Living with oropharyngeal dysphagia: effects of bolus modification on health-related quality of life--a systematic review. *Qual Life Res, 24*(10), 2447-2456. doi:10.1007/s11136-015-0990-y
- Taylor, C. M., Wernimont, S. M., Northstone, K., & Emmett, P. M. (2015). Picky/fussy eating in children: Review of definitions, assessment, prevalence and dietary intakes. *Appetite, 95*, 349-359. doi:10.1016/j.appet.2015.07.026
- Threats, T. T. (2007). Use of the ICF in dysphagia management. *Seminars in Speech & Language, 28*(4), 323-333.
- Twachtman-Reilly, J., Amaral, S. C., & Zebrowski, P. P. (2008). Addressing feeding disorders in children on the autism spectrum in school-based settings: physiological and behavioral issues. *Language, Speech & Hearing Services in the Schools, 39*(2), 261-272. doi:[https://dx.doi.org/10.1044/0161-1461\(2008/025\)](https://dx.doi.org/10.1044/0161-1461(2008/025))
- Van Ort, S., & Phillips, L. R. (1995). Nursing intervention to promote functional feeding. *Journal of Gerontological Nursing, 21*(10), 6-14.
- VanBiervliet, A., Spangler, P. F., & Marshall, A. M. (1981). An ecobehavioral examination of a simple strategy for increasing mealtime language in residential facilities. *J Appl Behav Anal, 14*(3), 295-305. doi:10.1901/jaba.1981.14-295

- Vucea, V., Keller, H. H., & Ducak, K. (2014). Interventions for improving mealtime experiences in long-term care. *J Nutr Gerontol Geriatr*, 33(4), 249-324.
doi:10.1080/21551197.2014.960339
- Westergren, A., Hagell, P., Wendin, K., & Sjödah Hammarlund, C. (2016). Conceptual relationships between the ICF and experiences of mealtimes and related tasks among persons with Parkinson's disease. *Nordic Journal of Nursing Research*, 36(4), 201-208.
doi:10.1177/2057158516642386
- World Health Organization. (2011). *International Classification of Functioning, Disability and Health*. Geneva: Author.
- Yilmaz, S., Basar, P., & Gisel, E. G. (2004). Assessment of feeding performance in patients with cerebral palsy. *International Journal of Rehabilitation Research*, 27(4), 325-329 325p.
- Zhang, M., Tao, T., Zhang, Z. B., Zhu, X., Fan, W. G., Pu, L. J., . . . Yue, S. W. (2016). Effectiveness of Neuromuscular Electrical Stimulation on Patients With Dysphagia With Medullary Infarction. *Arch Phys Med Rehabil*, 97(3), 355-362.
doi:10.1016/j.apmr.2015.10.104