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Patient Adherence to Dysphagia Recommendations: A Systematic Review

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Introduction

Adherence is a critical component of any treatment plan. To effectively achieve the desired result of a therapy intervention, the patient must participate in the recommended treatment, often independently without direct clinical supervision. Poor adherence to clinical recommendations may render evidence-based interventions ineffective, ultimately causing immense financial burden on the health-care system as a whole.(1–4) Patient non-adherence has been studied and discussed within a multitude of healthcare-related professions(5–9), but most often with a focus on medication adherence.(1, 10, 11) While there is an extensive literature base on adherence, the best methodology for improving patient adherence has yet to be definitively identified,(12, 13) and likely varies amongst patients and interventions.

Within the field of dysphagia, there are a variety of approaches that may be used to manage swallowing impairment. Treatments for dysphagia may include diet modifications, such as thickening liquids, changes in head posture that may improve safety of the swallow, and exercise programs targeting muscular adaptations.(14, 15) These approaches may be complex and time consuming to patients and their families, making adherence to these recommendations challenging. Almost all of these interventions require the patient to alter established patterns of behavior. The results of patients not adhering to dysphagia recommendations may be serious and can induce a higher risk for penetration or aspiration

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events. As a result, nonadherence to these recommendations could increase the likelihood of developing negative health outcomes, including malnutrition,(16) dehydration, and aspiration related pneumonia,(17) that increase mortality and decrease quality of life.(15, 18)

Family members or the healthcare team are often responsible, in part, for the execution of dysphagia treatment that may ultimately contribute to the overall quality of adherence, either in a positive or negative manner.(19) However, in cases where the patient is cognitively intact and able to make cognizant decisions, it is ultimately the patient's responsibility to participate in management of their dysphagia. To what degree patients participate is also the individual's choice, making the study of factors that contribute to patient-specific adherence with recommendations of the utmost importance.

Eating and drinking are critical for hydration and nutritional intake. People with dysphagia eat less food overall.(20) Beyond this, eating and dining have strong social and emotional connections. Altering these longstanding behavioral patterns across all social contexts can be complex and difficult for patients and their families. Given these complexities, issues that contribute to patient adherence with dysphagia-related recommendations must be studied directly and cannot be inferred from the general health adherence literature. Additionally, when evaluating current treatments and designing new interventions for dysphagia, adherence will substantially influence the results of a study and must be quantified to truly determine treatment efficacy. To effectively design studies focused on improving patient adherence to dysphagia management strategies, it is first necessary to gain an understanding of what is known about adherence to dysphagia-related recommendations. The aim of this systematic review was to address this gap in knowledge by systematically evaluating current knowledge regarding patient adherence to dysphagia recommendations. This review lays the groundwork for future studies and provides a benchmark of what is currently understood on this topic.

Methods

Inclusion and Exclusion Criteria

Overall, the goal of this review was to examine what is known about patient adherence to recommendations in dysphagia management. Methodology in preparing this review were rigorous, guided by the literature,(21) and in compliance with AMSTAR guidelines (A Measurement Tool to Assess the Methodological Quality of Systematic Reviews).(22) The development of our research question was formulated using the PICO framework: Population, Intervention, Comparison, Outcomes.(21)

- *Population:* All populations of patients who were diagnosed with dysphagia or were being treated for swallowing-related impairments were included in this review. This incorporated a variety of etiologies, including patients with stroke, head and neck cancer, Parkinson disease, or other diagnoses where patients experience dysphagia. We excluded studies examining patient populations with advanced conditions causing moderately or severely reduced cognition (e.g. severe traumatic brain injury, advanced stage dementia, late stage Parkinson

disease, etc.) or individuals that may require assistance to fully adhere to recommendations. Additionally, studies were excluded that examined only interventions for gastroesophageal reflux disease (GERD), laryngopharyngeal reflux (LPR), or other gastrointestinal issues.

- *Intervention:* Any swallowing intervention, recommendation, or therapy regimen to either improve swallow function or reduce risk of penetration or aspiration was included (e.g., exercise based therapies for the tongue, pharynx, or other swallowing muscles, postural changes, or diet modifications). Excluded were any therapies that were solely clinician-administered, such as treatments that can only be provided in an outpatient clinic or on an inpatient basis. Included interventions were required to have a component of self-delivery to allow examination of patient adherence. As such, papers focusing on staff or caregiver adherence were not included.
- *Comparison:* Contrasting and comparing adherence rates between studies identified in review search.
- *Outcomes:* Outcomes included proportions, percentages, or rates of adherence as reported in individual studies. Papers that did not report a percentage, proportion, or other numerical quantification of participant adherence to swallow intervention/recommendation(s) were not included in this review.

Databases and Search Terms

Five databases were searched (PubMed, Scopus, CINAHL, CENTRAL, and Web of Science) using terms developed by the first author (BNK) and a librarian (SJ) to capture all articles related to adherence, dysphagia, swallowing, or deglutition (For MeSH terms, please see Appendix). Our initial search was conducted in September of 2016, and an updated search was performed in April of 2017 to include the most recent publications in this review (for full list of citations, please visit <http://go.wisc.edu/4e5xzf>). The total number of abstracts identified from both searches, after de-duplication, was 2034 (Figure 1.) Grey literature (e.g. unpublished data, non-peer reviewed electronic sources)(23) and abstract-only texts were not included.

Abstract Review and Data Abstraction

Abstract, full text review, and data abstraction of articles written in English were performed by the first two authors (BNK and CKB) and with discrepancies settled by a third reviewer (NRP).(21) Reasons for exclusion of articles included: no direct measure of adherence (no objective data), exclusive focus on healthcare provider or family member adherence, review of literature rather than original report (Figure 1). During data abstraction, each article was assigned a quality rating between 1–5 according to the JAMA Quality Rating Scale for Studies and Other Evidence (www.jamanetwork.com). After final review, 12 articles were included in the final review and data abstraction (Figure 1). The following data were abstracted from each article:

1. Population studied, sample size (n), and age range
2. Study design (quality rating from JAMA)

3. Type of recommendation
4. Method for recording adherence
5. Main findings of adherence to specific recommendations
6. Barriers and facilitators to adherence (if identified; Table 2).

Results

Twelve articles that recorded patient adherence to dysphagia-related recommendations were included.

Populations Studied

In this review, nine of the twelve studies included head and neck cancer patients with dysphagia.(24–32) The remaining three studies included patients who were diagnosed with dysphagia of varied etiologies.(17, 33, 34) These etiologies were the following: stroke, hemilaryngectomy, cerebral spinal surgery;(33) Parkinson disease, airway malignancy, Huntington disease, motor neuron disease, Alzheimer’s disease, muscular dystrophy, tetraplegia, poliomyelitis;(17) brain lesion, deconditioning, unspecified neuromuscular or neurodegenerative disease, local structural lesion;(34) and cardiovascular accident.(17, 33) Studies were conducted in various settings, with all but one(17) in a hospital-based setting. Of these hospital based studies, many were administering outpatient treatments,(24–32)one included both inpatient and outpatients(34), and one with just inpatients.(33) The one study not conducted in a hospital setting incorporated a variety of settings including patients living at home, in institutional or rehab settings and hospital inpatients.(17)

The number of subjects in the relevant studies ranged from 6 to 497 (median = 78). One study(17) reported an age range and divided mean between two groups, another study(34) only reported mean age, and two others reported mean age and standard deviation rather than range and average age.(31, 32) One study(27) did not report an age range or mean. Including all studies that reported the age range and mean,(24–26, 28–30, 33) the collective age range for this review was 21–94, and the mean was 60.4 years.

Study Design

Two studies(31, 32) used a randomized control design, earning the highest JAMA rating of 1. One study(29) used a prospective cohort study design with a JAMA rating of 2. Four studies(17, 25, 27, 34) completed retrospective studies earning a JAMA score of 3. Five studies(24, 26, 28, 30, 33) earned a JAMA quality rating score of 4 and used the following designs: prospective cohort,(24) case-series(26, 28, 33) and pilot study.(30)

Types of Recommendations

Most of the studies identified in this search (8/12) reported adherence to swallowing strength-based exercise regimens.(24–26, 28–32) Three studies tracked adherence for use of diet modifications/compensatory strategies.(17, 33, 34) One study did not specify the details of therapy interventions.(27)

Recording of Adherence

Nine studies recorded adherence based on self-report using journals, logs, checklists and diaries.(17, 25, 26, 28–32, 34) One study reported data retrieved from the SwallowIT® application and clinician tracked adherence data.(32) Two studies(24, 33) reported patient adherence data obtained by SLP documentation and observation.

Adherence Findings

Two methods were used to report adherence in the studies that qualified for inclusion in this review: 1) calculating an “average adherence rate” to recommendations using either actual observations of behavior or tallied exercise logs,(30, 32, 33) *or* 2) dividing participants into groups based on level of adherence, with each “adherence group” then expressed as a percentage of the total number of participants in the study.(17, 24–29, 31, 34) An example of “grouped adherence” reporting is found in a paper by Hutcheson and colleagues(25) where participants who performed exercises 4 or less times a day were considered “partially” adherent, and those who performed exercises 4 or more times a day were considered “fully” adherent. We calculated three pooled adherence rates based on these methods of reporting:

- The pooled adherence for the three studies(30, 32, 33) that calculated an “average adherence rate” was 51.3% (SD= 35.3%).
- The pooled adherence rate for studies that used “grouped adherence”: was 51.9% (SD= 19.67, median=57%), however this rate combines participants who were “fully” adherent with those who were “partially” adherent.(17, 24–29, 31, 34)
- For three studies of the studies that reported “grouped adherence”, they also specified a sub-group with either “high” or “full” levels of adherence. For these studies, the pooled average of high levels of adherence was 21.9% (SD= 7.8%). (24, 25, 28)

Adherence Barriers/Facilitators/Support

Six of the studies identified potential barriers to adherence.(17, 24, 28, 32, 33) The most frequently reported barriers were difficulty of the task(24, 28, 32, 34) and fatigue.(24, 28, 32) Only two studies(28, 33) reported potential facilitators of improved adherence. These included both internal factors relating to the participants themselves (high motivation, social support, psychological well being and increased physical condition) and external factors relating to the environment or other variables (having written instructions about exercises and eating alone). Additionally, two studies(28, 30) reported providing weekly phone calls to their subjects to encourage participation in treatment.

Discussion

In our systematic review of the literature, we identified twelve full text articles that reported and discussed patient adherence to recommendations in the treatment of dysphagia (Table 1). Of the papers included in our review, some examined adherence as a main outcome, while others considered adherence as a secondary aim or in conjunction with the main outcome of interest. The first article we identified was published in 1996.(33) In 2016, three

papers on this topic were published, which suggests that interest in reporting and understanding adherence may be increasing. The average adherence rate to dysphagia recommendations from studies that reported an overall level of average patient adherence ranged between 21.9% for those patients considered to be “fully adherent” to 52% for those with “average adherence”. When comparing these averages to the average adherence reported in an extensive review of 569 healthcare-related adherence studies(35) (24.8% adherence rate, range 4.6%–100%), it appears that adherence to dysphagia recommendations is similar or higher than average. However, with only twelve studies identified in our search, it is abundantly clear that there is a lot more to learn about adherence to dysphagia recommendations within our field.

Patient Populations

Dysphagia treatment serves diverse populations across the lifespan. The acute or chronic nature of the primary diagnoses of patients with dysphagia, or comorbid conditions are likely to be factors impacting the degree of adherence to a specific therapy or recommendation.(4, 36) Thus, consideration should be given to the primary diagnoses of patients identified in our review.

Of the twelve papers identified in this review, a majority (9/12) had a focus on adherence with recommendations in patients with head and neck cancer. For patients with head and neck cancer, symptoms impacting swallowing may fluctuate throughout treatment,(37, 38) which may contribute to changes in adherence. In fact, one of the studies in our review showed how adherence to exercise decreased throughout treatment, from 70% at 6-weeks of intensity-modulated radiation therapy to only 38% adherence at 12 weeks.(29) The severity of swallowing deficits may also depend on the approach used during tumor intervention (e.g. chemoradiation therapy vs. intensity modulated chemoradiation therapy vs. surgical intervention).(39, 40) These competing factors are variable and are likely to impact the overall severity of impaired swallowing,(41–43) making this a challenging population to study. Consequently, adherence rates from a head and neck cancer population are unique and cannot be readily generalized to other dysphagia-related conditions because of these distinct features.

Five out of nine head and neck cancer studies in this review had a prophylactic treatment component. Prophylactic exercises are prescribed in an attempt to strengthen multiple muscle groups involved in swallowing before chemoradiation treatment with the goal of preventing or diminishing the devastating effects radiation has on swallowing function.(44, 45) Prophylactic management of any kind is administered before the onset of symptoms. We postulate that adherence to this type of proactive treatment may vary based (1) on the treatment type or recommendation; or (2) whether or not the person is currently experiencing symptoms from their diagnos(es) or condition(s). These additional factors may affect generalizability of this information to other types of treatment for dysphagia.

The three studies identified in our review that included etiologies other than head and neck cancer examined at least 16 different primary diagnoses. As discussed with head and neck cancer, these conditions are complex and contain their own characteristics and related complications with swallowing. While the importance and impact of the research presented

here regarding head and neck cancer populations cannot be overstated, continued focused work to determine the factors influencing adherence across other patient groups is needed.

Tracking Adherence

The method used to track adherence is an important consideration. The quality of data collected depends on a reliable approach to track and measure adherence. In all but three of the twelve studies examined, a self-report approach for obtaining adherence-related data was used. Of the three studies using different measures to track adherence, one video-recorded patients eating and directly observed whether they were adherent to recommendations,(33) another used record reviews ability to perform the exercises.(24) Although this third approach could be considered a measure of knowledge or ability to perform the exercises rather than truly reflecting adherence, the authors justify this measurement saying, “It was not possible for participants to demonstrate competency to the speech pathologist at later follow-up appointments if they had not practiced regularly at home” (p. 1708).

These varied approaches to tracking and measuring adherence raise the question of what method is best for determining how well a patient adheres to recommendations. Unfortunately, the best method for tracking adherence still remains to be definitely decided, although experts who have studied adherence offer some advice.(4) It has been recommended that adherence be recorded using multiple approaches so that data between sources can be triangulated for the most accurate view of patient adherence.(4) In general, there are two broad domains encompassing measurement and reporting of adherence: 1) “Continuous” measurement is defined as “offer[ing] three or more ordered response categories, or is based on multiple adherence criteria, or uses a reliable, validated continuous measure”; or, 2) “Dichotomous” measurement, defined as “involv[ing] two categories (adherent vs. not adherent), sometimes based on a percentage determined by the researchers,” (p. 803).(4) (Figure 2.) By combining approaches for adherence tracking methodology through continuous and dichotomous strategies and comparing data using multiple sources, the most complete picture of adherence is likely to be established.

Self-report of adherence alone can introduce bias into a data set given that individuals are likely to over-report participation.(46) In a study comparing self-report measures (interview, diary, questionnaire) with “nonself-report measures” (pill count, plasma drug concentration, electronic monitors, etc), researchers found that certain self-report measures were more concordant with nonself-report measures.(47) For example, interviews had a significantly lower association with nonself-report measures than did diaries or questionnaires, indicating that not all self-report measures will provide the same accuracy.(47) Although there are many ways to use self-reported adherence, it is still unknown which measure is best for tracking home exercise programs.(48) Recently, devices used regularly in swallowing therapy, such as the SwallowStrong® device and the Iowa Oral Performance Instrument (IOPI), have been designed to include objective reporting of patient adherence.(49–51) Use of such devices gives potential for multiple, more accurate measures of adherence within dysphagia therapy. We conclude and encourage that future adherence research in dysphagia include multiple, both continuous and dichotomous measures of adherence wherever possible.

Barriers and Facilitators

Of the twelve articles included in this review, half of them attempted to identify barriers and or facilitators to adherence (Table 2). The method by which this information was obtained varied among the papers and included: phone interview sometime after completion of the study,(24, 34) immediate informal interview upon trial completion,(33) statistical comparison of characteristics of patients who were adherent and those who were not,(17) weekly phone interviews during treatment,(28) and daily log-book entries or clinician-led questions after completion of a session.(32) Barriers identified are likely to vary depending upon the specific treatment modality. For example, “dissatisfaction with texture or taste” was related to a diet or liquid modification recommendation while “difficulty in performing exercises” was specific to an exercise regimen. However, several barriers identified in our review could relate to a variety of treatments, including depression, questioning of motivation or relevance, therapy buy-in, forgetting to complete tasks, or living at home. Some barriers, if corrected, could serve as facilitators. For example, negative social implications of following recommendations could be a barrier, but having a social support network that encourages completion of recommendations could serve as a facilitator. Similarly, overall decreased physical condition could reduce adherence with a therapy regimen, but improved or increased physical condition might recover adherence. One paper excluded from our review(52) sought to identify barriers and facilitators using a unique approach by informally interviewing exclusively nonadherent patients. Patient interviews using sound qualitative methodology could be a useful approach to gain more specific information on barriers and facilitators to adherence in future studies.

According to the World Health Organization 2003 comprehensive report on adherence, the main barriers to adherence to patient-specific interventions in healthcare involve decreased education and skills in self-management, decreased motivation, and a lack of support to incur behavioral change.(53) While these barriers don't align one-for-one with the barriers identified in this review, many have similar themes such as low motivation and decreased self-management to complete a task (denial, task difficult, remembering). Other reasons for non-adherence identified in areas of health care include forgetfulness, substance abuse, fear of disclosure, work and family responsibilities(54), lack of interest, lack of time, medical conditions, and family priorities.(55) Facilitators have been identified in other areas too, including flexibility in program timing, home-based exercises, exercises that are easy to perform,(55) feeling of self-worth, seeing positive effects of medications, understanding the need of adherence, and use of reminder tools.(54) While some of these barriers and facilitators discussed from other realms of healthcare could apply to patients with dysphagia, it is easy to identify those that would not apply in dysphagia management. For example, from the HIV literature the number of pills required and negative side effects of drug therapy would not apply, or from the osteoporosis literature, fear of falling or injury and reduced mobility would not be barriers necessarily affecting someone with dysphagia. Because dysphagia diagnoses are so broad and may involve one or more comorbidities and complex therapy approaches, more work is needed to identify barriers and facilitators relevant to patients with dysphagia.

Other Considerations

The papers in this review cover many topics related to adherence. However, there are several areas that have yet to be explored. One specific topic that has received little attention is the relationship between dose of behavioral or exercise therapy and patient adherence. One study in our review(31) discussed this specifically, saying that there is a “clear lack of consensus regarding optimal dose of swallow therapy and therefore acceptable compliance rates” (p. 331). This becomes apparent as we examine the varied doses in this review, the wide range of therapies available, and the diverse definitions of adherence. Dose frequency is cited by the World Health Organization as one of the top barriers to adherence in therapy interventions.(53) Thus, finding the minimum effective dose necessary to induce physiological change is a critical component in development of treatment recommendations that maximize patient adherence.(53, 56) Further exploration is needed to determine effects of dose on physiological and biological components of exercise interventions.

Another topic not covered in this review is external influences on patient adherence, such as health-systems related factors.(57) In this review, we only included studies that reported a quantifiable measure of patient-specific adherence. However, there were several studies we uncovered that explored other persons and factors that may influence patient adherence including speech-language pathologists,(58) nursing staff,(59) and the healthcare team.(60) Rosenvinge and Starke (2005) conducted a study where they trained health care team members and observed patient adherence to dysphagia recommendations before and after training.(60) They demonstrated an improvement in adherence with recommendations for fluid consistencies, amounts given, and safe swallow guidelines after a staff education and training intervention to improve understanding of dysphagia recommendations.(60) Further, the level of caregiver involvement and support is important to consider when examining adherence in patients with cognitive impairment, where there is reliance on a caregiver to carry out treatment plans.

In addition to the external factors influencing patient adherence, internal patient-specific factors such as self-efficacy must also be considered.(61) Classically identified as a critical component of social cognitive theory,(62) self-efficacy is the expectation of how one will be able perform a “specific task”.(63) In lay terms, self-efficacy is the level of self-confidence someone has about their own ability to successfully complete a task,(63, 64) in this case the “specific task” would be follow-through with recommendations for management of dysphagia. In fact, both self-efficacy and “expectation of outcome” were both found to predict adherence to an exercise-based program in a classic study,(65) where self-efficacy was even more so predictive than expectations alone. Improving self-efficacy through educational interventions can be beneficial to improving adherence in patients with chronic disease.(66) This idea of enhancing self-efficacy in populations of patients who have dysphagia requires further study and should be examined in future work focused on in improving adherence.(61)

Limitations

Other factors to consider in adherence research are the innate limitations that come with the nature of this work. Many of the studies examined in this review acknowledged and

discussed these limitations, and they should be considered and addressed in future research. First, studies examining adherence to therapy regimens might have an inherently biased sample: those who agreed to participate in an intervention study may be more motivated than those who declined inclusion, and thus may demonstrate higher adherence than the general population. One article in our review(29) mentioned this as a limitation, stating that head and neck cancer patients in their study could have been more motivated to complete the exercises, hence why they enrolled in the study. Several papers cited measuring adherence via self-report(17, 28, 29, 32, 34) and having a small sample size(17, 28, 31–34) as limitations.

A limitation the authors noted while performing this review was lack of specificity when describing therapy interventions a lack of detail when describing methods of tracking adherence. It is often difficult to ascertain from the methods described what the specific intervention involved or what exact method of tracking was used. General rather than specific terms were used to describe adherence-tracking mechanisms, making it difficult to pinpoint the exact methodology used to record or measure adherence and reducing interpretability. More detailed descriptions of the interventions studied will be necessary to improve the design and execution of future work in this area.

Future Directions

The papers identified in this review provide a basis for future exploration of adherence to dysphagia recommendations. In addition, this systematic review identifies a gap in knowledge on this topic: there are very few studies in a large body of literature examining dysphagia interventions that actually account for and report on adherence. Further, within these studies that do measure and track for adherence, often it is difficult to discern the methodology used for recording adherence. Without these data, interpretation of outcomes and effectiveness of interventions are limited as the actual level of patient performance is unknown.

In designing future studies, we recommend consideration of the method of tracking, sample size, recruitment bias, external influences on patient adherence, and adequate characterization and description of the patient populations and treatment interventions. Further, including more detailed methodology and descriptions of interventions provided should bolster the external validity of findings. For behavioral and exercise interventions, identifying the minimal dose needed for biological and physiological change will be important for creating and modifying current interventions to maximize opportunities for patient adherence. Additional work must be done to identify the best methods of tracking adherence specific to dysphagia treatment as well. Qualitative methods may be useful in identifying barriers and facilitators to adherence by using patient-led interview to discuss reasons for adherence or nonadherence. Further, theoretical modeling of adherence has yet to be fully explored. Experts insist that the use of theoretical modeling in adherence research is critical, yet understudied.(67) An appropriate theoretical model for adherence to dysphagia therapy should be identified and explored to provide a better framework for understanding and improving adherence. The current state of a majority of research in our field often includes adherence as a secondary aim or afterthought to explain a lack of

significant findings. Studies with primary aims to systematically quantify and interpret adherence to recommendations will be required.

Conclusions

Patient adherence is an important consideration in treatment development and implementation. Although dysphagia treatment is broad and complex, we only identified twelve studies reporting patient adherence data. We first conclude that very little is known or understood about patient adherence recommendations in the field of dysphagia research. Considering how important patient adherence is to the success of many of these recommendations, it is a critical topic that must be addressed in future studies to improve patient outcomes and quality of life. A majority of what is understood about adherence comes from other health disciplines. However, we must take on the challenge of directly studying adherence within our own field rather than assuming cross-over from other disciplines. We hope and anticipate that the information provided in this review will serve as a platform for the future study of adherence within dysphagia management.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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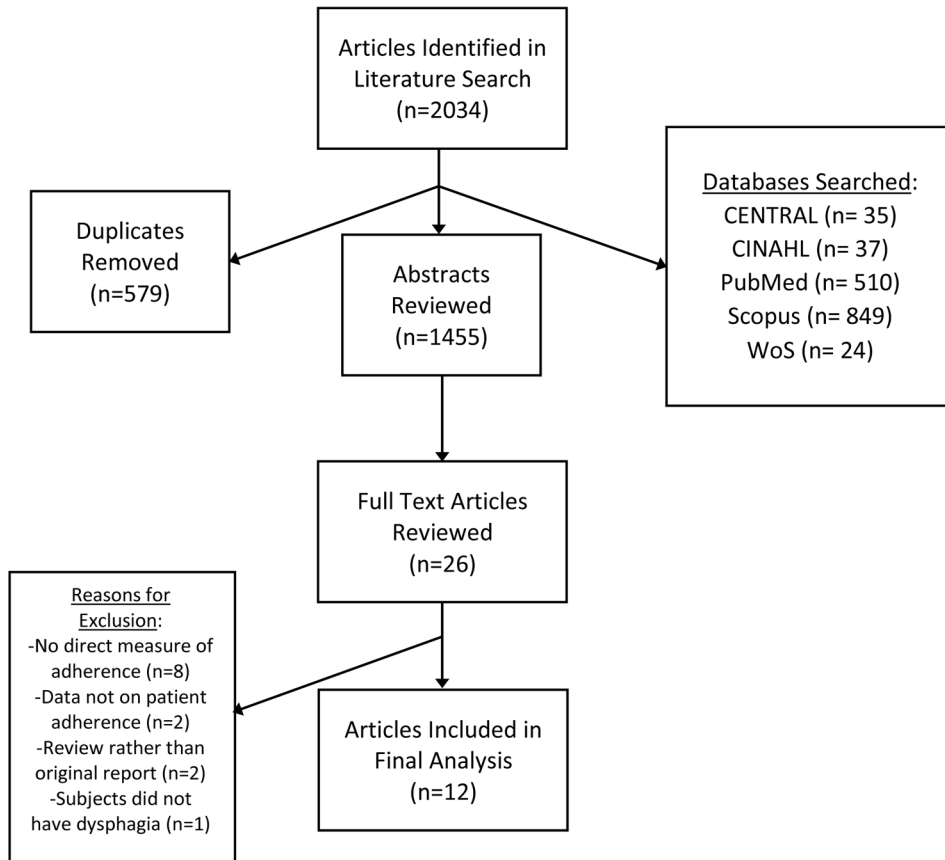


Figure 1.

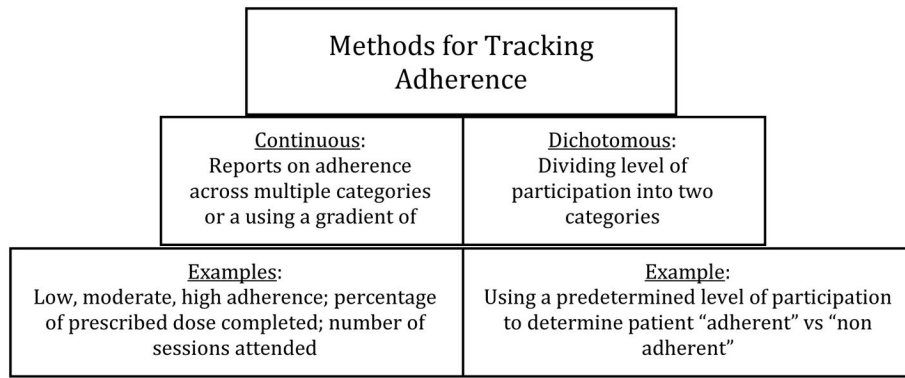


Figure 2.

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Table 1

Results of full text abstraction after systematic review. For specific barriers and facilitators reported, please see Table 2.

Author(s) Year	Study Population (n)	Age Range (mean; +/-)	Design (JAMA Quality Rating)	Recommendations	Adherence Tracking	Adherence Findings	Barriers/ Facilitators Identified?
Leiter & Windsor 1996	Dysphagia, varied etiologies (n=8)	69-80 (72)	Case-Series (4)	Swallowing Recommendations (Posturing, bolus size, swallow + cough, alternating food/liquid)	Observation	36% Average Adherence	Yes
Low et al 2001	Dysphagia, varied etiologies (n=140)	55-94 (77.4 & 79) ^a	Retrospective Cohort (3)	Swallowing Recommendations (modified foods/liquids, techniques)	Self-Report	67% Adherent w/swallow recs 84% Adherent w/liquid recs	Yes
Starmer et al 2011	HNC (n=118)	<60 years	Retrospective Cohort (3)	Participation in SLP Therapy (before, during, after HNC tx)	Records Reviewed	80% Adherence (multidisciplinary) 17% Adherence (outside referral)	No
Shinn et al 2013	HNC (n=19)	31-79 (57)	Prospective Cohort (4)	Exercise	Documented by SLP	32% Partially Adherent 13% Fully Adherent	Yes
Hutcheson et al 2013	HNC (n=497)	38-80 (56)	Retrospective Observational (3)	Exercise	Self-Report	32% Partially Adherent 26% Fully Adherent	No
Duarte et al 2013	HNC (n=85)	22-91 (60)	Case-Series (4)	Exercise	Self-Report	67% Adherent	No
Shim, Oh, & Han 2013	Dysphagia, varied etiologies (n=62)	(64.1)	Retrospective Chart Review (3)	Thickeners	Self-Report	57% Adherence (90% of Inpatients 41% of Outpatients) Adherent) ³	Yes
Crossen et al 2014	HNC (n=33, 64% participated in exercise program)	21-77 (60)	Case-Series (4)	Exercise	Self-Report	42% Low Adherence 30% Moderate Adherence 27% High Adherence	Yes
Crossen et al 2016	HNC (n=50)	40-77 (61)	Prospective Cohort Study (2)	Exercise	Self-Report (diary)	70% Adherence at 6-weeks 38% Adherence at 12 weeks	No
Krisciunas et al 2016	HNC (n=153)	61.9 (+/- 9.6)	Randomized Control Trial (1)	Exercise + Electrical Stimulation	Self-Report (checklist)	54% Adherent	No
Wall et al 2016	HNC (n=71)	59.50 (+/- 6.15)	Randomized Control Trial (1)	Exercise (prophylactic)	Self-Report (log-books), SwallowIT, Clinician tracked	27% Average Adherence	Yes
Hajdu et al 2017	HNC (n=6)	42-67 (57)	Pilot Study (4)	Exercise	Self-Report (logbook, weekly phone calls)	92% Average Adherence	No

^aThis study reported means for two groups, the first number (77.4) represents average age of surviving subjects, the second number represents average age of subjects who died. +/- Represents standard deviation for the mean age that was reported in two studies

Table 2

Barriers and facilitators identified in systematic review.

Barriers	Facilitators
1 Denial of Problem ^a	1 Written instructions ^b
2 Task was difficult ^{a,d,e,f}	2 Eating alone ^b (avoid distractions) ^e
3 Remembering to perform exercises ^a	3 Increased physical conditions ^e
4 Pain ^{a,f}	4 Psychological well-being ^e
5 Fatigue/Decreased condition ^{a,e,f}	5 High Motivation ^e
6 Too busy to complete exercises ^{a,f}	6 Social support ^e
7 Question relevance or low motivation ^{b,e}	
8 Living at home ^c	
9 Dissatisfaction with texture or taste ^d	
10 Dyspepsia (indigestion) ^d	
11 Social implications ^e	
12 Depression ^f	

^aShinn et al 2013;

^bLeiter & Windsor 1996;

^cLow et al 2001;

^dShim, Oh, Han 2013;

^eCnossen et al 2014;

^fWall et al 2017