Review Article

Insights Into Oropharyngeal Dysphagia From Administrative Data and Clinical Registries: A Literature Review

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Purpose: The call for data-driven health care has been bolstered by the digitization of medical records, quality initiatives, and payment reform. Administrative databases and clinical registries are increasingly being used to study oropharyngeal dysphagia and to facilitate data-driven decision making. The objective of this work was to summarize key findings, etiologies studied, data sources used, study objectives, and quality of evidence of all original research articles that have investigated oropharyngeal dysphagia or aspiration pneumonia using administrative or clinical registry data to date.

Method: A literature search was completed in MEDLINE, Scopus, and Google Scholar (January 1, 1990, to February 1, 2017). Each study that met inclusion criteria was rated for quality of evidence on a 5-point scale.

Results: Eighty-four research articles were included in the final analysis ($n = 221\text{--}1,649,871$). Over the past 20 years, the number of new publications in this area

has quintupled. Most of the administrative database and clinical registry studies of dysphagia have been retrospective cohort studies and cross-sectional studies and limited to quality of evidence levels of 3–4. In these studies, much has been learned about risk factors for dysphagia and pneumonia in defined populations and health care costs and usage. Little has been gleaned from these studies regarding swallowing physiology or dysphagia management.

Conclusions: Investigators are just beginning to develop the methods to study oropharyngeal dysphagia using administrative data and clinical registries. Future research is needed in all areas, from the fundamental issue of how to identify individuals with dysphagia with high sensitivity in these data sets to evaluating treatment effectiveness.

Supplemental Material: <https://doi.org/10.23641/asha.6066515>

The consequences of oropharyngeal dysphagia are devastating and can include weight loss, dehydration, reduced quality of life, depression, aspiration pneumonia, and death (Altman, Yu, & Schaefer, 2010; Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002; Han et al., 2011). Despite these poor outcomes, evidence regarding the pathogenesis and management of oropharyngeal dysphagia is insufficient (Foley, Teasell, Salter, Kruger, & Martino, 2008; Langmore et al., 2015; Langmore & Pisegna, 2015; Perry & Love, 2001; Robbins, Langmore, Hind, & Erlichman, 2002). For example, in 2009, the National Quality Forum removed swallow screening from their list of endorsed standards for stroke prevention and management due to lack

of well-designed research (National Quality Forum, 2009). Across health care, tools associated with clinical informatics, such as information science, computer technology, and statistical techniques, are being used to guide clinical decision making (Wan, 2006). Large repositories of health information, such as administrative databases and clinical registries, are increasingly being used as an input for clinical informatics initiatives (Wan, Lin, & Ma, 2002). The potential to use clinical informatics processes to assess quality of care and develop clinical treatment algorithms for oropharyngeal dysphagia could be an important direction for this field. An initial step will be to understand how administrative databases and clinical registries have been leveraged for dysphagia research to date.

“Administrative claims data,” “health care administrative data,” and “health care utilization data” are synonymous terms for data that are collected for medical billing purposes. For the past four decades, medical conditions have been investigated in administrative health care databases using code-linked procedures, treatments, and

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Editor-in-Chief: Krista Wilkinson

Editor: Julie Barkmeier-Kraemer

Received September 19, 2017

Revision received November 25, 2017

Accepted December 27, 2017

https://doi.org/10.1044/2018_AJSLP-17-0158

Disclosure: The authors have declared that no competing interests existed at the time of publication.

outcomes (Sarrazin & Rosenthal, 2012). The first study of oropharyngeal dysphagia using administrative data was published in 1998 (Grant, Rudberg, & Brody, 1998), suggesting that this body of work is in its infancy. Administrative data have many strengths that are well matched to the study of dysphagia, including real-world treatment settings, unselected populations, large sample sizes, and data that span many years and varied health care settings.

Patient registries are an alternative data source that could be exploited for dysphagia research. Patient registries are collections of standardized clinical data obtained from populations that share a health condition, treatment, or health-related device. The data serve scientific, clinical, or policy purposes. Clinical registries are well suited to study conditions treated by allied health professionals (physical therapy, occupational therapy, speech-language pathology [SLP]), because evaluation and treatment data that may not be easily represented with medical codes can be collected. For example, swallow screen results are collected through Get With the Guidelines-Stroke, a clinical stroke registry through the American Heart Association (Bettger et al., 2015).

Administrative databases and clinical registries are increasingly being used to study oropharyngeal dysphagia, but no review of the existing literature has been published. A better understanding of the patterns of health care data (e.g., populations targeted, questions asked) could refine the design of future dysphagia research and support clinical informatics initiatives. The objective of this work was to summarize key findings, etiologies studied, data sources used, study objectives, and quality of evidence of all original research articles that have investigated oropharyngeal dysphagia or aspiration pneumonia using administrative or clinical registry data to date.

Method

A literature search was completed in MEDLINE, Scopus, and Google Scholar to identify all oropharyngeal dysphagia or aspiration pneumonia investigations within administrative data sets and patient registries from January 1, 1990, through February 1, 2017. National and state data sets were considered. Searches included combinations of dysphagia-related terms (“dysphagia,” “oropharyngeal dysphagia,” “aspiration pneumonia”), relevant International Classification of Diseases (ICD) codes, Current Procedural Terminology codes, and specific claims databases and patient registries (e.g., “MarketScan,” “Ontario Stroke Registry”). A description of the administrative data sources most frequently used in oropharyngeal dysphagia research is provided (see Table 1). The review was limited to articles that reported dysphagia or aspiration pneumonia data. Also, bibliographies of all selected articles were searched for articles that met the inclusion criteria. Articles that mentioned “dysphagia” in the context of esophageal dysphagia were excluded. A flow diagram of the search and study selection process is provided (Supplemental Material S1).

A total of 84 original research articles published between 1998 and 2017 were ultimately included in the review.

The analyses have been organized into two main sections. First, the Summaries of Population-Specific Findings section includes synopses of clinically relevant data from the reviewed articles. It is organized by patient population and subdivided into Epidemiology and Pathophysiology, Dysphagia Diagnosis, Dysphagia-Related Sequelae, Health Care Utilization, and Dysphagia Treatment topics. The patient populations in this section are ordered by article frequency (Stroke, Cervical Spinal Surgery, Head and Neck Cancer [HNC], and Gastrostomy, Dementia, and/or Long-Term Care). Patient populations with three or fewer publications in our review included benign central nervous system (CNS) lesions, Parkinson’s disease (PD), amyotrophic lateral sclerosis, traumatic brain injury, voice disorders, and all-comers with dysphagia, and these publications have been summarized in the “Other” section near the end. There were several articles that investigated subpopulations of elderly individuals (e.g., older adults with dementia), and these articles have been grouped according to disease, rather than a section solely dedicated to older adults. In the second section, Summary of Administrative Data/Clinical Registry Use, the overarching themes related to the Populations and Data Sources, Study Objectives, and Level of Evidence Ratings from the 84 articles are discussed.

Ratings of the quality of evidence were assigned to each study using a scale adapted from the Oxford 2011 Levels of Evidence (Oxford Centre for Evidence-Based Medicine, Table 2; Durieux, Passeau, & Howick, 2011; Howick et al., 2011; OCEBM Levels of Evidence Working Group et al., 2011). The original Oxford 2011 Levels of Evidence table assigns hierarchies of evidence to specific clinical questions (“How common is the problem?” “Does this intervention help?”). We adapted the scale to reflect the broad range of clinical questions covered in the 84 reviewed articles (1 = *properly powered and conducted randomized clinical trial*; 2 = *well-designed controlled trial without randomization, prospective comparative cohort trial*; 3 = *case-control studies, retrospective cohort study*; 4 = *case series with or without intervention, cross-sectional study*; 5 = *opinion of authorities, case reports*).

Summaries of Population-Specific Findings

Stroke

To date, administrative and clinical registry studies of stroke have largely focused on epidemiology, swallowing screening biases, and the relationships between dysphagia, pneumonia, and death (Articles 1–37; Table 3). The largest gap in dysphagia knowledge for the stroke population was treatment.

Epidemiology and Pathophysiology

Oropharyngeal dysphagia has been reported in 9.1%–50.5% of patients following stroke in clinical registries (Flowers, Silver, Fang, Rochon, & Martino, 2013; Guyomard et al., 2009; Saposnik et al., 2008, 2011). Asians have at least 60% greater odds of having dysphagia following

Table 1. Administrative data sources commonly used in dysphagia research (in alphabetical order).

Name	Source	Overview	Variables
MarketScan Research Data	Truven Health Analytics	Health care claims data from commercial insurance, Medicare supplemental, and Medicaid	<ul style="list-style-type: none"> Demographics Integrated patient-level data across settings (inpatient, outpatient, drug, laboratory, etc.)
Medicare Provider and Analysis Review	Centers for Medicare & Medicaid Services	Hospital inpatient services data from Medicare beneficiaries	<ul style="list-style-type: none"> Demographics Hospital provider number Diagnoses/procedure codes Payments Diagnoses
Minimum Data Set	Centers for Medicare & Medicaid Services	Data obtained as a part of the federally mandated, comprehensive assessment of residents in Medicare- and Medicaid-certified nursing homes	<ul style="list-style-type: none"> Several categories of functioning, such as cognition, communication, physical functioning
National Inpatient Sample	Agency for Healthcare Research and Quality	Hospital discharge data from all hospitals participating in health care cost and utilization project	<ul style="list-style-type: none"> Demographics Diagnoses/procedures Admission/discharge dates Discharge status Payer information
Surveillance, Epidemiology, and End Results (SEER)–Medicare	National Cancer Institute	Cancer registries data linked to Medicare claims data	<ul style="list-style-type: none"> Clinical, demographic, cause of death information from SEER Medicare claims data for covered health care services

stroke than Whites (Bussell & Gonzalez-Fernandez, 2011; Gonzalez-Fernandez, Kuhlemeier, & Palmer, 2008). This finding remained robust after adjusting for age, sex, hemiplegia, aphasia, and number of comorbidities (Gonzalez-Fernandez et al., 2008). Aspiration pneumonia was also more common in Asians (Bussell & Gonzalez-Fernandez, 2011). These findings may be related to stroke characteristics, such as stroke type (ischemic vs. hemorrhagic; Bussell & Gonzalez-Fernandez, 2011; Gonzalez-Fernandez et al., 2008). Dysphagia following stroke was also more common in African Americans than in Whites, but the disparity was not as large as the Asian comparison (Bussell & Gonzalez-Fernandez, 2011; Gonzalez-Fernandez et al., 2008). These data suggest that dysphagia screening may be particularly important in minorities.

No specific information about swallowing physiology or dysphagia severity was included in any of the reviewed articles.

Dysphagia Diagnosis

Dysphagia screening by nursing staff prior to oral intake is often considered a stroke quality of care indicator.

Swallow screen data have been reported in 41%–84% of patients following stroke in clinical registry studies in the United States, Canada, and Germany (Flowers et al., 2013; Fonarow et al., 2010; Hall et al., 2013; Hinchey et al., 2005; Joundi et al., 2017; Kapral et al., 2013; Masrur et al., 2013; Muller-Barna, Boy, Hubert, & Haberl, 2015; Saltman, Silver, Fang, Stamplecoski, & Kapral, 2015; Saposnik et al., 2009; Stoeckle-Roberts et al., 2006; Xian et al., 2012). Screening rates have been shown to vary with patient age, race (Black, Asian, Hispanic > White), stroke type (intracranial hemorrhage > ischemic stroke), stroke severity, off-hour admission, July admission, community versus in-hospital stroke, insurance status, academic hospital status, and history of atrial fibrillation (James et al., 2014; Joundi et al., 2017; Masrur et al., 2013; Park, Redelmeier, Li, Pongmoragot, & Saposnik, 2015; Reeves et al., 2009; Saltman et al., 2015; Saposnik et al., 2009; Smith et al., 2009; Xian et al., 2014). Screening rates do not vary by patient sex, smoking status, or weekend admission (Ali, Smith, Bhatt, Fonarow, & Schwamm, 2013; Fang, Saposnik, Silver, & Kapral, 2010; Kapral et al., 2011; Starr, Becker, & Tirschwell, 2016). There has been some exploration into increasing dysphagia screening

Table 2. Levels of evidence description.

Level	Descriptions
Level 1	Properly powered and conducted randomized clinical trial; systematic review with meta-analysis
Level 2	Well-designed controlled trial without randomization; prospective comparative cohort trial
Level 3	Case-control studies; retrospective cohort study
Level 4	Case series with or without intervention; cross-sectional study
Level 5	Opinion of authorities; case reports

Note. Scale was adapted from the 2011 Oxford Centre for Evidence-Based Medicine Levels of Evidence.

Table 3. Stroke articles overview.

Article no.	Reference	Data source	Level of evidence ^a	n
1.	Ali et al. (2013)	GWTC-Stroke	4	4,305
2.	Andaluz & Zuccarello (2008)	NIS	4	905,152
3.	Bettger et al. (2015)	GWTC-Stroke	4	849,780
4.	Burneo et al. (2010)	RCSN	3	5,027
5.	Bussell & Gonzalez-Fernandez (2011)	MedPAR	4	382,959
6.	Fang et al. (2010)	RCSN	3	20,657
7.	Finlayson et al. (2011)	RCSN	3	8,251
8.	Flowers et al. (2013)	RCSN	4	221
9.	Fonarow et al. (2010)	GWTC-Stroke	4	1,000,000
10.	Gonzalez-Fernandez et al. (2008)	MIRCaI, SPARCS	4	123,023
11.	Guyomard et al. (2009)	Norfolk and Norwich University Hospital Stroke Register	4	2,983
12.	Hall et al. (2013)	RCSN	4	3,191
13.	Hinchey et al. (2005)	SPIN	4	2,532
14.	Hinchey et al. (2010)	SPIN	2	3,311
15.	James et al. (2014)	GWTC-Stroke	4	95,986
16.	Joundi et al. (2017)	Ontario Stroke Registry	3	7,171
17.	Kapral et al. (2011)	RCSN	3	4,046
18.	Kapral et al. (2013)	Ontario Stroke Registry	3	243,287
19.	Katzan et al. (2003)	MedPAR	3	11,286
20.	Katzan et al. (2007)	MedPAR	3	11,286
21.	Lakshminarayan et al. (2010)	Paul Coverdell National Acute Stroke Registry	4	18,017
22.	Masrur et al. (2013)	GWTC-Stroke	4	314,007
23.	Muller-Barna et al. (2015)	Bavarian Stroke Registry	4	7,386
24.	Ovbiagele et al. (2006)	California Acute Stroke Prototype Registry	4	663
25.	Park et al. (2015)	RCSN	3	10,319
26.	Reeves et al. (2009)	GWTC-Stroke	4	222,514
27.	Saltman et al. (2015)	Ontario Stroke Registry	3	29,810
28.	Saposnik et al. (2008)	RCSN	3	3,631
29.	Saposnik et al. (2009)	RCSN	3	3,631
30.	Saposnik et al. (2011)	RCSN	4	9,304
31.	Smith et al. (2009)	GWTC-Stroke	4	479,284
32.	Starr et al. (2016)	GWTC-Stroke	4	2,737
33.	Stoeckle-Roberts et al. (2006)	GWTC-Stroke	3	740
34.	Wilson (2012)	NIS	4	183,976
35.	Wilson & Howe (2012)	Multiple sources	3	NA
36.	Xian et al. (2014)	GWTC-Stroke	4	123,623
37.	Xian et al. (2012)	GWTC-Stroke	4	438

Note. GWTC-Stroke = Get With the Guidelines-Stroke registry; MedPAR = Medicare Medical Provider Analysis and Review Data; MIRCaI = Medical Information Reporting for California; NIS = National (Nationwide) Inpatient Sample; RCSN = Registry of the Canadian Stroke Network; SPARCS = Statewide Planning and Research Cooperative System; SPIN = Stroke Practice Improvement Network; NA = not applicable.

^aScale was adapted from the 2011 Oxford Centre for Evidence-Based Medicine Levels of Evidence (see Table 2 for scale description).

rates using various programs (Hinchey et al., 2010; Stoeckle-Roberts et al., 2006).

A decision analysis model that was populated with published data has been used to evaluate the effectiveness of swallowing evaluation methods (Wilson & Howe, 2012). The conclusion was that videofluoroscopic swallowing study (VFSS) performed on all patients following stroke was more effective, in terms of cost and mortality prevention, than alternatives (clinical exam alone or clinical exam followed by VFSS as clinically indicated).

Dysphagia-Related Sequelae

Administrative studies have significantly improved our understanding of pneumonia rates and risk factors for pneumonia and pneumonia-related death in patients with stroke. During inpatient admission for stroke, pneumonia has been reported in 5.7%–10% of adults (Katzan, Cebul, Husak, Dawson, & Baker, 2003; Masrur et al., 2013;

Ovbiagele, Hills, Saver, & Johnston, 2006; Wilson, 2012). Patient factors associated with pneumonia following stroke include being male, being older, being admitted from a skilled nursing facility or nursing home, and several comorbid conditions (Finlayson et al., 2011; Katzan et al., 2003; Masrur et al., 2013; Ovbiagele et al., 2006; Wilson, 2012). Dysphagia and several related variables (i.e., gastrostomy tube, nasogastric tube, enteral/parenteral nutrition, weight loss) have also been significantly associated with pneumonia during stroke admission (Wilson, 2012). Higher pneumonia rates have been reported at hospitals that lack a formal dysphagia screening protocol (Hinchey et al., 2005). One study reported a higher pneumonia rate in unscreened patients with stroke than in patients who passed a screening (Lakshminarayan et al., 2010). These data suggest the inadequacy of clinical judgment for dysphagia risk.

Pneumonia rates vary with stroke severity (Masrur et al., 2013). In administrative database studies, proxies for

stroke severity, such as paralysis, are often used during analysis. Several conditions associated with greater impairment following stroke (e.g., paralysis, mechanical ventilation, use of feeding tube) have been linked to pneumonia risk (Katzan et al., 2003; Wilson, 2012). It has been suggested that dysphagia may be a reasonable proxy for stroke severity. In two studies, dysphagia was strongly associated with hemiplegia and aphasia, two common proxies for stroke severity (Bussell & Gonzalez-Fernandez, 2011; Tirschwell et al., 2002). Further research is needed to understand the relationship between dysphagia and stroke severity given conflicting results from a seizure study (Burneo, Fang, & Saposnik, 2010).

The relationships between dysphagia, pneumonia, and mortality have been frequently studied. Dysphagia has been associated with increased mortality at 7 days, 30 days, and 1 year following stroke (Guyomard et al., 2009; Saposnik et al., 2008). Pneumonia significantly increased the 30-day mortality following stroke, even after statistical adjustments were made for confounds such as admission severity and propensity for pneumonia (Katzan et al., 2003; Ovbiagele et al., 2006; Wilson, 2012). Wilson (2012) found that patients with the lowest propensity for pneumonia had the highest relative risk of pneumonia-associated death (Wilson, 2012). This suggests that dysphagia screening is important for all patients following stroke, regardless of apparent risk factors.

Health Care Utilization

Dysphagia has been shown to increase stroke hospitalizations by 5 days (Guyomard et al., 2009), and pneumonia has been shown to increase hospital length of stay by at least 8 days (Lakshminarayan et al., 2010; Ovbiagele et al., 2006). In patients with intracerebral hemorrhage, aspiration pneumonia was the comorbid diagnosis that was most strongly associated with increased length of stay (Andaluz & Zuccarello, 2008). In 2012, the marginal cost of pneumonia or the increase in the total admission cost resulting from pneumonia was estimated to be \$23,102 (Wilson, 2012).

Dysphagia and its sequelae increase the need for post-acute stroke care, such as inpatient rehabilitation, skilled nursing facility, or home health services. The two clinical features most predictive of need for post-acute care have been reported to be swallow screen “failure” and inability to walk on the second day of stroke admission (Bettger et al., 2015). Furthermore, patients with pneumonia during stroke admission were 70% more likely to require inpatient or home health care services than those without pneumonia (Katzan, Dawson, Thomas, Votruba, & Cebul, 2007). Discharge to home has been identified as a surrogate indicator for a good outcome (Andaluz & Zuccarello, 2008). Receiving aftercare is a life-altering consequence of stroke, and dysphagia is a strong predictor of the level of care needed.

Dysphagia Treatment

Very little has been learned about dysphagia treatment from administrative or clinical registry data sets. The

Bavarian Stroke Registry has included “speech and language therapy for patients with dysphagia/dysphasia/dysarthria” within 2 days of stroke onset as a stroke quality indicator and have reported their compliance rates (Muller-Barna et al., 2015). The Registry of the Canadian Stroke Network has reported the frequency of “speech therapy” following stroke, but care was not subcategorized by impairment type (dysphagia, dysarthria, dysphasia; Saposnik et al., 2008).

Cervical Spinal Surgery

Cervical discectomy and fusion are common surgical procedures to treat degenerative spinal disease and other issues. Oropharyngeal dysphagia is a relatively frequent complication of these procedures and may be related to prevertebral soft tissue swelling; impaired cricopharyngeal opening; or injury to the hypoglossal, glossopharyngeal, or recurrent laryngeal nerves. To date, administrative data research has largely been used to explore how dysphagia rates varied by surgical type, patient demographics, provider variables, time, and treatment (Articles 38–51; Table 4). The largest gaps in knowledge for this population were pathophysiology, dysphagia evaluation, and treatment.

Epidemiology and Pathophysiology

Clinical variables associated with dysphagia following cervical spinal surgery include older age (> 65 years), male sex, African American and Asian races, various comorbidities, and treatment by a higher volume surgeon (Boakye, Patil, Santarelli, & Ho, 2008; Cole, Veeravagu, Zhang, & Ratliff, 2017; Singh, Marquez-Lara, Nandyala, Patel, & Fineberg, 2013; Starmer et al., 2014; Wang, Chan, Maiman, Kreuter, & Deyo, 2007). Dysphagia is more likely to be reported 30 days following surgery than during the index admission (Veeravagu, Cole, Azad, & Ratliff, 2015). All of these variables can be exploited when identifying patients most at risk for dysphagia.

Higher dysphagia rates have been reported with an anterior surgical approach (2.5%–4.1%) as compared to posterior approach (0.84%–1.55%; Boakye et al., 2008; Singh et al., 2013; Starmer et al., 2014; Veeravagu et al., 2016). Even higher dysphagia rates have been reported for a combined anterior and posterior fusion (11.3%; Veeravagu et al., 2016). Dysphagia is also more common following multilevel fusion as compared to single-level cervical fusion (Singh et al., 2013; Veeravagu, Cole, Jiang, & Ratliff, 2014). Dysphagia/dysphonia rates following atlantoaxial fusion have also been reported (Derman et al., 2016). It is likely that these rates are underestimated due to undiagnosed dysphagia and undercoding (González-Fernández, Gardyn, Wyckoff, Ky, & Palmer, 2009).

As surgical approaches have evolved over time, the outcomes associated with various agents have been tracked with administrative data. Local steroid injection has been reported to significantly decrease dysphagia rates in the 90 days following three-level anterior cervical discectomy and fusion (Cancienne et al., 2015). Local injection of recombinant human bone morphogenetic protein has

Table 4. Cervical spinal surgery articles overview.

Article no.	Reference	Data source	Level of evidence ^a	n
38.	Boakye et al. (2008)	NIS	4	58,115
39.	Cahill et al. (2017)	NIS	4	328,468
40.	Cancienne et al. (2015)	PearlDiver Patient Records Database	3	245,754
41.	Cole et al. (2014)	MarketScan	3	91,543
42.	Cole et al. (2017)	MarketScan	3	24,461
43.	Derman et al. (2016)	SPARCS	4	1,559
44.	Fineberg et al. (2013)	NIS	4	233,755
45.	Goode et al. (2014)	MarketScan	3	61,937
46.	Singh et al. (2013)	NIS	4	159,590
47.	Starmer et al. (2014)	NIS	4	1,649,871
48.	Veeravagu et al. (2016)	MarketScan	3	35,962
49.	Veeravagu et al. (2015)	MarketScan	3	188,965
50.	Veeravagu et al. (2014)	MarketScan	3	28,777
51.	Wang et al. (2007)	NIS	4	932,009

Note. NIS = National (Nationwide) Inpatient Sample; SPARCS = Statewide Planning and Research Cooperative System.

^aScale was adapted from the 2011 Oxford Centre for Evidence-Based Medicine Levels of Evidence (see Table 2 for scale description).

been associated with higher rates of dysphagia and dysphagia-related readmission following cervical fusion (Cahill, Chi, Day, & Claus, 2017; Cole, Veeravagu, Jiang, & Ratliff, 2014; Fineberg, Ahmadinia, Oglesby, Patel, & Singh, 2013; Goode, Richardson, Schectman, & Carey, 2014). In 2008, the U.S. Food and Drug Administration issued a warning against the use of this biologic in the cervical spine (Cole et al., 2014; Fineberg et al., 2013).

Dysphagia Diagnosis

No studies in our review focused on dysphagia diagnosis methods in this population.

Dysphagia-Related Sequelae

Higher rates of mortality, aspiration pneumonia, gastrostomy feeding tube placement, and tracheostomy have been associated with patients with dysphagia following anterior cervical discectomy and fusion (Singh et al., 2013; Starmer et al., 2014).

Health Care Utilization

Patients who have undergone cervical fusion and have postsurgical dysphagia tend to have longer hospital length of stay and higher hospitalization costs than those without dysphagia (Singh et al., 2013). The incremental cost of dysphagia following anterior cervical discectomy and fusion has been reported to be \$3,694 to \$4,500 (Starmer et al., 2014; Veeravagu et al., 2016). Furthermore, post-operative dysphagia has a strong influence on total health care costs up to 90 days following surgery (Starmer et al., 2014; Veeravagu et al., 2016).

Dysphagia Treatment

Very little has been learned about dysphagia treatment following cervical spine surgery from administrative data. In one investigation, only 0.2% of patients with dysphagia following anterior cervical discectomy had “speech

therapy/dysphagia training” (Starmer et al., 2014). This rate of treatment was likely underestimated because ICD-9 therapy codes, rather than Current Procedural Terminology codes, were used in the analysis.

HNC

HNC articles primarily focused on the influence of clinical and treatment variables on dysphagia-related sequelae, such as weight loss, gastrostomy placement, and pneumonia (Articles 52–60; Table 5). All other areas (epidemiology, pathophysiology, dysphagia diagnosis and treatment, health care utilization) have considerable gaps in knowledge.

Epidemiology and Pathophysiology

Patients with HNC who are treated with chemotherapy may be particularly vulnerable to dysphagia and its sequelae. In a comparison of surgery, radiation, chemotherapy, or a combined approach for HNC, dysphagia and pneumonia rates were highest in individuals treated with chemoradiation (Francis, Weymuller, Parvathaneni, Merati, & Yueh, 2010).

Dysphagia Diagnosis

No studies in our review focused on dysphagia diagnosis methods in this population.

Dysphagia-Related Sequelae

Gourin et al. (2015) found that chemoradiation treatment had particularly devastating effects in elderly patients with laryngeal cancer. Long-term dysphagia, weight loss, and gastrostomy tube placement were all significantly associated with initial chemoradiation treatment (Gourin et al., 2015).

Less provider experience and preadmission weight loss are two drivers of poor outcomes in patients with HNC. Patients with HNC who were treated with intensity-modulated

Table 5. Head and neck cancer articles overview.

Article no.	Reference	Data source	Level of evidence ^a	n
52.	Boero et al. (2016)	SEER-Medicare	3	6,212
53.	Chan et al. (2013)	NIS	4	7,791
54.	Francis et al. (2010)	SEER-Medicare	3	8,002
55.	Genther & Gourin (2014)	NIS	4	61,740
56.	Gourin et al. (2015)	SEER-Medicare	3	2,370
57.	Gourin et al. (2014)	NIS	4	93,663
58.	Mulvey et al. (2016)	NIS	4	80,514
59.	Semenov et al. (2012)	NIS	4	93,663
60.	Starmer et al. (2015)	SEER-Medicare	3	2,370

Note. NIS = National (Nationwide) Inpatient Sample; SEER-Medicare = Surveillance, Epidemiology, and End Results Program–Medicare.

^aScale was adapted from the 2011 Oxford Centre for Evidence-Based Medicine Levels of Evidence (see Table 2 for scale description).

radiation therapy had lower rates of mortality and aspiration pneumonia when treated by high-volume radiation oncologists, as compared to low-volume practitioners (Boero et al., 2016). Weight loss prior to HNC ablative surgery has been associated with wound healing complications and surgical site infection. These data remained significant when several confounds, including dysphagia, were controlled (Gourin, Couch, & Johnson, 2014). These data speak to the importance of identifying weight loss early in the diagnostic process.

Another poor outcome of HNC, ventilator-associated pneumonia, has been investigated in an administrative database study. Following a threat by the Centers for Medicare & Medicaid Services to discontinue payment for ventilator-associated pneumonia on the grounds that it is preventable, Semenov, Starmer, and Gourin (2012) found pneumonia risk factors that were not entirely preventable in patients with HNC. This study illustrates how national administrative samples can be used to investigate proposed health care reform.

Health Care Utilization

Costs of care and length of hospital stay have been estimated for various HNC populations, including patients with paragangliomas and older adults following ablative surgery (Chan, Li, & Gourin, 2013; Genther & Gourin, 2014; Gourin et al., 2014; Semenov et al., 2012). Dysphagia has been found to increase the length of hospital stays and health care costs in elderly individuals following ablative surgery for HNC (Genther & Gourin, 2014). One care paradigm for some patients with HNC is palliation. In one study, only 5% of patients with incurable HNC received palliative care services (Mulvey, Smith, & Gourin, 2016). Despite the unique end of life issues for patients with dysphagia and terminal HNC, there was no difference in the palliative care rate between patients with dysphagia and those without dysphagia (Mulvey et al., 2016).

Dysphagia Treatment

The effect of SLP evaluation and management on patients with HNC has begun to be investigated using the

Surveillance, Epidemiology, and End Results Program (SEER)–Medicare linked database. Patients with laryngeal cancer who received SLP evaluation/treatment for dysphagia and/or alaryngeal speech options had significantly reduced odds for dysphagia, stricture, weight loss, airway obstruction, and pneumonia (Starmer et al., 2015). Despite these promising data, only 6% of the patients received SLP care during their initial cancer treatment (Starmer et al., 2015).

Gastrostomy, Dementia, and/or Long-Term Care

Because of the overlapping topics of gastrostomy tube use, dementia, and residence in long-term care facilities among the studies, these articles have been grouped for analysis. In patients with gastrostomy tubes, administrative databases have primarily been used to investigate patient demographics, aspiration pneumonia risk, and mortality. Administrative studies of patients with dementia and/or elderly individuals living in long-term care have primarily focused on health issues such as undernutrition, gastrostomy tube usage, and health care costs (Articles 61–75; Table 6). Areas where more gastrostomy research are needed include patient selection algorithms for gastrostomy tube placement and health care utilization comparison studies, particularly for individuals under age 65 years and for dysphagic subpopulations (cerebral palsy, etc.). For individuals with dementia and individuals living in long-term care facilities, large gaps in knowledge were identified in effective dysphagia diagnosis methods, treatment, and health care utilization comparisons for various care paradigms.

Epidemiology and Pathophysiology

Using the Minimum Data Set (MDS), swallowing problems have been identified in 10%–25% of long-term care residents (Challa, Sharkey, Chen, & Phillips, 2007; Keller & Hirdes, 2000; Langmore, Skarupski, Park, & Fries, 2002). Other MDS data relevant to the discussion of tube feeding have been reported in a study of individuals living in nursing homes (e.g., rates of having a living will, medical power of attorney, specific directive not to provide tube feeding, Do Not Hospitalize order, and Do Not

Table 6. Gastrostomy, dementia, and/or long-term care articles overview.

Article no.	Reference	Data source	Level of evidence ^a	n
61.	Ahronheim et al. (2001)	MDS	4	57,029
62.	Baine & Kazakova (2005)	MedPAR	3	30,998
63.	Challa et al. (2007)	MDS	4	128,514
64.	Grant et al. (1998)	Hospital claims, social security administration files, health care financing administration claims	3	81,105
65.	Keller & Hirdes (2000)	MDS	4	13,446
66.	Kuo et al. (2009)	MDS	3	5,209
67.	Langmore et al. (2002)	MDS	4	102,842
68.	Mitchell & Kiely (2001)	MDS	4	1,773
69.	Mitchell et al. (2003)	MDS	3	1,057
70.	Murray et al. (2003)	MDS Plus	3	11,150
71.	Rudberg et al. (2007)	MDS Plus	3	1,545
72.	Siddique et al. (2000)	NIS, MarketScan	3	299,149
73.	Tian et al. (2012)	MarketScan	3	772
74.	Tian et al. (2013)	MarketScan	3	8,977
75.	Zhao et al. (2008)	MarketScan	3	100,436

Note. MedPAR = Medicare Medical Provider Analysis and Review Data; MDS = Minimum Data Set; MDS Plus = Minimum Data Set Plus; NIS = National (Nationwide) Inpatient Sample.

^aScale was adapted from the 2011 Oxford Centre for Evidence-Based Medicine Levels of Evidence (see Table 2 for scale description).

Resuscitate order; Ahronheim, Mulvihill, Sieger, Park, & Fries, 2001).

There are striking variations in gastrostomy tube placement rates by region, race, and country of residence (Ahronheim et al., 2001; Grant et al., 1998; Kuo, Rhodes, Mitchell, Mor, & Teno, 2009; Mitchell & Kiely, 2001; Rudberg, Egleston, Grant, & Brody, 2007). Gastrostomy rates are much higher in African Americans than in Whites, possibly due to differences in stroke risk, dysphagia rates, and attitudes about life-sustaining therapies (Ahronheim et al., 2001; Grant et al., 1998; Kuo et al., 2009; Rudberg et al., 2007).

Dysphagia Diagnosis

No studies in our review focused on dysphagia diagnosis methods in these populations.

Dysphagia-Related Sequelae

Dysphagia can contribute to undernutrition and pneumonia risk in individuals living in nursing homes and in those with dementia. Chronic undernutrition, as determined by the body mass index, has been found in 12%–28% of nursing home residents (Challa et al., 2007; Keller & Hirdes, 2000). Swallowing problems have been found to be a significant contributor to undernutrition, even when resident, facility, and geographic variables were adjusted (Challa et al., 2007; Keller & Hirdes, 2000). For-profit facilities have also been associated with undernutrition (Challa et al., 2007); however, the relationship between the profit status of care facilities and dysphagia management has not been investigated.

In patients with Alzheimer's disease, pneumonia was the most common reason for inpatient hospital admission (Zhao, Kuo, Weir, Kramer, & Ash, 2008). In a

comprehensive investigation of patients living in nursing homes, Langmore et al. (2002) concluded that some of the best predictors of aspiration pneumonia were feeding dependence, mechanically altered diet, weight loss, tube feeding, suctioning, and swallowing problems (Langmore et al., 2002). This retrospective study had a much larger sample size than her previous prospective landmark study of a similar topic, and the studies shared many of the same findings (Langmore et al., 1998).

One care option, gastrostomy tube placement, has generally been associated with poor outcomes in patients with advanced dementia. Higher 1-year mortality rates and gastrostomy-related complications requiring hospital transfer have been reported in this population (Kuo et al., 2009). Despite poorer outcomes, up to 50% of this population has a gastrostomy tube placed, most often during an acute hospitalization for pneumonia, dehydration, or dysphagia (Kuo et al., 2009). Gastrostomy tube placement has also been associated with some nursing home characteristics, such as having a full-time SLP on staff (Mitchell, Kiely, & Gillick, 2003). SLPs can assist with sensitive and evidence-based decision making with the patient, caregivers, and family, particularly during acute hospitalizations for dysphagia-related sequelae.

When considering patients without dementia, dysphagia is a risk factor for aspiration pneumonia even following gastrostomy tube placement. In one study, approximately 10% of individuals admitted to a hospital for aspiration pneumonia had a gastrostomy tube already or received one during that admission (Siddique et al., 2000). Another study found an association between aspiration pneumonia and hospital admission for depression in elderly individuals (Baine & Kazakova, 2005). Mortality rates at various time points following gastrostomy tube placement have been

reported for individuals over 65 years and those living in long-term care facilities (Grant et al., 1998; Rudberg et al., 2007). Among patients with dysphagia who lost the ability to independently self-feed, gastrostomy tube placement has been associated with improved mortality rates; however, both groups had high 1-year mortality rates (Rudberg et al., 2007). As most of the mortality data have been reported in patients with dementia and individuals over 65 years, the utility of gastrostomy tube placement in many other populations (cerebral palsy, HNC) remains unclear.

Another use of administrative data in patients with Alzheimer's disease has been evaluated medication adherence methods (oral vs. transdermal) based on dysphagia status (Tian, Abouzaid, Chen, Kahler, & Kim, 2012).

Health Care Utilization

Health care costs have been estimated for patients with Alzheimer's disease (Tian et al., 2013; Zhao et al., 2008). Patients with Alzheimer's disease and dysphagia have more hospitalizations (i.e., all-cause, Alzheimer-related), more emergency room visits, and higher health care costs than those without dysphagia (Tian et al., 2013). High costs have also been associated with gastrostomy tube-associated pneumonia in a study of individuals across the life span. In 1995, the average inpatient hospitalization for gastrostomy tube-associated pneumonia lasted more than 20 days and cost \$26,618 (Siddique et al., 2000).

Dysphagia Treatment

No studies in the review reported on the relationships between SLP care and dysphagia in these populations. Rehabilitation in general (speech-language therapy, physical therapy, or occupational therapy) of nursing home residents has been associated with a greater likelihood of community discharge and a lower risk of death (Murray, Singer, Dawson, Thomas, & Cebul, 2003).

Other

Patient populations with fewer than three or fewer publications in our review included benign CNS lesions (Cole et al., 2015; Connolly et al., 2015; Ward et al., 2012), PD (Fernandez & Lapane, 2002; Huse et al., 2005), amyotrophic lateral sclerosis (Williams, Fitzhenry, Grant, Martyn, & Kerr, 2013), traumatic brain injury (Gabella, Mangione, Hedegaard, & Kelly, 2007), voice disorders (Roy, Kim, Courey, & Cohen, 2016), and all-comers with oropharyngeal dysphagia (Altman et al., 2010; Articles 76–84; Table 7). Among the publications included in this “Other” category, epidemiology of dysphagia was the topic most frequently studied. Large gaps in knowledge were found for dysphagia diagnosis and treatment, dysphagia-related sequelae, and health care utilization.

Summary of Administrative Data/ Clinical Registry Use

Populations and Data Sources

The number of new oropharyngeal dysphagia publications in administrative data and clinical registry articles has quintupled over the past 20 years (see Figure 1). The data sources used most frequently in the reviewed articles included clinical registries, National (Nationwide) Inpatient Sample, MarketScan, and the MDS (see Figure 2 and Table 1). The limitations of administrative data sources have previously been reported (Ching, 2014; Haut, Pronovost, & Schneider, 2012; Sarrazin & Rosenthal, 2012). Currently, the largest limitation of using administrative data to study oropharyngeal dysphagia is the low sensitivity of relevant billing codes. In a recent study of the agreement between VFSS results from medical charts and billing codes in a hospital's administrative database, ICD-9 code 787.2 (“dysphagia”) was found to have low sensitivity, with only 20.2% of patients with dysphagia per VFSS having received the 787.2 code (González-Fernández et al., 2009). The code had high specificity, meaning that when the code was present in a patient's billing data, the patient was truly dysphagic in over 94% of the cases (González-Fernández et al., 2009). These data may suggest that ICD-9 code 787.2 may be best used to identify patients for within-group studies of dysphagia.

One method for identifying a greater proportion of the dysphagic patients in an administrative database is to use surrogate medical codes. In addition to a dysphagia code, Gonzalez-Fernandez et al. (2008) included ICD-9 codes for aspiration pneumonia and presence of a feeding tube in the absence of coma to generate a cohort of individuals likely to have dysphagia (Gonzalez-Fernandez et al., 2008). Statistical analysis of the 787.2 subset of patients yielded similar results to the complete set of patients, suggesting that the additional search probes may be valid for some investigations (Gonzalez-Fernandez et al., 2008). Collectively, these data suggest that the rates of oropharyngeal dysphagia are underestimated using billing codes, but there are some methods (surrogate billing codes, within-group studies) to circumvent this issue when designing a study.

The populations targeted in the studies of this review appeared to have been influenced by two main factors, dysphagia-specific data availability and billing code specificity (Figure 2). First, the availability of dysphagia-specific data in specific clinical registries and the MDS appears to have strongly influenced the research topics that have been explored to date. For example, stroke was unsurprisingly the most frequently studied population in the review, partly due to the high prevalence and seriousness of dysphagia in this population. However, three quarters of the stroke papers reported clinical registry data, suggesting that the richness of dysphagia-specific data captured by stroke registries encourages research exploration (see Table 3). In our search, stroke was the only population with dysphagia

Table 7. Other articles overview.

Article no.	Population	Reference	Data source	Level of evidence ^a	n
76.	Dysphagia ^b	Altman et al. (2010)	NHDS	4	271,983
77.	Benign CNS lesion	Cole et al. (2015)	MarketScan	3	476
78.	Benign CNS lesion	Connolly et al. (2015)	MarketScan	3	2216
79.	PD	Fernandez & Lapane (2002)	SAGE, MDS	3	15,237
80.	TBI	Gabella et al. (2007)	MDS	4	16,478
81.	PD	Huse et al. (2005)	MarketScan	3	40,032
82.	Voice	Roy et al. (2016)	MarketScan	4	60,773
83.	Benign CNS lesion	Ward et al. (2012)	NIS	4	17,281
84.	ALS	Williams et al. (2013)	CMS longitudinal claims data set	3	399

Note. ALS = amyotrophic lateral sclerosis; CNS = central nervous system; CMS = Centers for Medicare & Medicaid Services; MDS = Minimum Data Set; NHDS = National Hospital Discharge Summary; NIS = National (Nationwide) Inpatient Sample; PD = Parkinson's disease; SAGE = Systematic Assessment of Geriatric Drug Use via Epidemiology database; TBI = traumatic brain injury.

^aScale was adapted from the 2011 Oxford Centre for Evidence-Based Medicine Levels of Evidence (see Table 2 for scale description). ^bAll-comers with dysphagia (various etiologies).

data gleaned from a clinical registry, suggesting that developing dysphagia-specific data within clinical registries for many other populations (e.g., PD, HNC) may be useful. The other clear example of data availability encouraging research were the MDS studies of individuals with dementia or those living in long-term care facilities. As the data were obtained as a part of the federally mandated, comprehensive assessment of all residents in Medicare- and Medicaid-certified nursing homes, an unselected subpopulation is captured. The MDS includes diverse clinical data, such as a general description of swallowing function and feeding independence. It should be kept in mind that the MDS is typically filled out by a nurse, but an SLP can contribute to relevant sections when available.

Second, billing code specificity likely influenced the populations that have been investigated. Oropharyngeal dysphagia is a symptom of a disease or process, and identifying the etiology of dysphagia is often important in research. Oropharyngeal dysphagia billing codes typically do not specify etiology (e.g., ICD-10, R13.10–R13.14), with an exception of dysphagia following cerebrovascular disease (i.e., ICD-10, I69). Despite this, investigators have

found methods to study oropharyngeal dysphagia using administrative data. For example, cervical spinal surgery patients, the second most frequently targeted population found in the review, is an apt topic for administrative database study because the underlying etiology and intervention are discrete and linked to specific billing codes (see Figure 2). An investigator may have reasonable confidence in ascribing dysphagia etiology because the timing of the index event (surgery) and dysphagia diagnosis code can be evaluated. On the other hand, there are many patients with dysphagia that would be difficult to identify with billing codes because of nonspecific billing codes, high rates of comorbidity, and complex health histories. For example, there were no studies in the review of individuals with dysphagia strictly due to aging. An important future direction will be to develop research methods that improve the accuracy of identifying dysphagia etiology using administrative data sources.

Study Objectives

To date, administrative data and clinical registries have primarily been used to study the epidemiology of oropharyngeal dysphagia rather than its treatment. In order of frequency, the objectives of the articles reviewed included characterizations of populations with dysphagia, calculations of dysphagia rates following surgery or radiation, explorations of provider variables, estimations of costs of dysphagia or its sequelae, and reports of outcomes using SLP evaluation and treatment codes (see Figure 3). The aspects of subpopulations of individuals with dysphagia that have been characterized using administrative data and clinical registries have been vast (see Summaries of Population-Specific Findings section). Frequently, the rates of dysphagia following various treatments (e.g., cervical spinal fusion, resection of benign CNS tumors, radiation therapy for HNC) have been investigated. When interpreting prevalence rates, it should be remembered that oropharyngeal dysphagia is typically underestimated in administrative data (González-Fernández et al., 2009).

Figure 1. The number of new oropharyngeal dysphagia publications in administrative data and clinical registry articles has quintupled over the past 20 years. Articles are shown by publication year ($n = 84$).

Figure 2. Publication frequency by patient population (A) and data source (B). Populations included patients following stroke, cervical spinal surgery, older adults, head and neck cancer (HNC), gastrostomy, dementia, benign central nervous system (CNS) lesions, Parkinson's disease (PD), amyotrophic lateral sclerosis (ALS), dysphagia (with no other population designation), traumatic brain injury (TBI), and voice disorders. Data sources included clinical registries, National (Nationwide) Inpatient Sample (NIS), MarketScan family of databases, Minimum Data Set (MDS), other databases, Medicare Provider and Analysis Review (MedPAR), state databases, and Surveillance, Epidemiology, and End Results Program–Medicare (SEER-Medicare; $n = 84$). Thirteen publications were counted in more than one category in A. For example, articles that studied subpopulations (e.g., elderly individuals with dementia) led to more than one population being counted for some articles. In B, six publications used more than one database, and each was counted. Articles about elderly individuals were counted in the “elderly” category when no other population (e.g., dementia, gastrostomy) was designated ($n = 5$) in B.

The relationships between health care provider variables and clinically relevant outcomes such as mortality, pneumonia, and gastrostomy tube placement rates have begun to be explored using these data sets. The provider variables most frequently studied include the teaching status of a

Figure 3. Objectives related to dysphagia in administrative data and clinical registry articles. Objectives included characterizing dysphagic populations or risk factors, reporting dysphagia rate following surgery or radiation, exploring provider variables, calculating the cost of dysphagia or its sequelae, tracking outcomes using SLP evaluation and treatment codes, and observational treatment studies ($n = 84$). Several of the publications had multiple objectives, and each was counted. There were no observational studies that compared dysphagia treatments. SLP = speech-language pathology; eval. = evaluation.

hospital, presence of an SLP on staff, and physician experience with specific procedures and populations (e.g., radiation therapy, stroke care; Boero et al., 2016; Mitchell et al., 2003; Saposnik et al., 2008). The costs associated with various health conditions and health care paradigms have also begun to be explored in subpopulations with dysphagia using administrative data. Studies have included cost estimates of single populations (e.g., pneumonia following acute stroke) and cost comparisons (costs of care for individuals with Alzheimer's disease with dysphagia as compared to those without dysphagia; Katzan et al., 2007; Tian et al., 2012). A rarer use of administrative data is to explore SLP services for specific populations. In two studies, SLP evaluation and treatment codes were used to better understand care of individuals with oropharyngeal dysphagia in the context of anterior cervical discectomy and laryngeal cancer surgical treatment (see Figure 3; Starmer et al., 2014, 2015).

Level of Evidence Ratings

The majority of the reviewed articles received evidence ratings of “3” and “4” using the adapted Oxford Centre for Evidence-Based Medicine Scale (see Tables 2–7).

Study designs primarily included retrospective cohort studies and cross-sectional studies. The retrospective cohort studies were often used to investigate incidence and causes of dysphagia and related sequelae. Cross-sectional studies were often used to investigate prevalence. Strengths of cross-sectional and cohort study designs using administrative data are that they can have large sample sizes, be readily performed because the data has already been collected, and may be less expensive than a prospective study. For example, sample size for the 84 articles reviewed ranged from 221 to 1,649,871 subjects (see Tables 3–7). Disadvantages are that there is little control over the variable of interest and potential confounders. Of the 84 articles reviewed, the highest evidence rating was a “2” for a well-designed controlled trial without randomization of various interventions to improve adherence to stroke performance measures at hospitals in the Stroke Practice Improvement Network Registry (Hinchey et al., 2010). Across the field, investigators are learning ways to increase the quality of administrative data research with various tools, such as software packages to select well-matched control groups. For example, in an investigation of the direct medical costs of PD, SAS SurveySelect Procedure was used to select a control group that matched the sample size and distribution of age, sex, and insurance type from the MarketScan database (Huse et al., 2005). Development and use of tools such as these could improve the quality of evidence from dysphagia studies within administrative data and clinical registries.

Limitations

A limitation of the present work is that studies investigating similar topics using nonadministrative data sources have been excluded, so there is a risk that a reader could overgeneralize the results found in the Summaries of Population-Specific Findings section. Limitations of administrative claims research in general have been well described and include medical coding changes over time, coding inconsistencies, diagnostic/procedure underreporting, influential reimbursement policies, problems inherent to retrospective data, and the absence of test results, vital signs, and patient-reported outcomes (Ching, 2014; Haut et al., 2012; Sarrazin & Rosenthal, 2012). Clinical registries resolve some of these issues. In our review, the only articles that investigated dysphagia or aspiration pneumonia using clinical registry data were for individuals with stroke. Given the prevalence of dysphagia and the diverse range of associated primary diagnoses, adding swallowing data to more clinical registries is warranted. Other options for improving the study of dysphagia using administrative data studies include supplementing the data with electronic medical records, using multiple administrative data sources, or adding a prospective study arm to the research design.

Conclusion

To date, most of the administrative database and clinical registry studies of dysphagia have been retrospective

cohort studies and cross-sectional studies and limited to evidence levels of 3–4. The sources most frequently used were clinical registries, National (Nationwide) Inpatient Sample, and MarketScan family of databases. The populations most frequently studied were patients following stroke or cervical spinal surgery and individuals over 65 years. These populations may have been particularly accessible because of the specificity of medical and procedure codes that are currently available. Across the reviewed articles, the epidemiology and costs of dysphagia were more frequently studied than treatment. A couple of the more novel studies have identified biases in patient selection for dysphagia stroke screening and evaluated adherence to medication type (oral vs. transdermal) in populations with dysphagia. Using administrative data and clinical registries to better understand dysphagia and to direct its management is still in its infancy. In the future, all elements of the research process need to be improved, from developing methods to identify individuals with dysphagia in claims data with higher sensitivity to establishing clinical registries that capture universally meaningful outcome measures.

Acknowledgment

This project was funded by the National Institutes of Health NIDCD grant R01 DC4336, which was awarded to Susan L. Thibeault.

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