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Signs of Aspiration in Adults with Down Syndrome: Prevalence as Determined Using A Water-Swallowing Screen and Caregiver Report

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Abstract

Background: Pneumonia and aspiration pneumonia are major causes of mortality in adults with Down syndrome (DS). However, dysphagia and swallowing safety have not been well studied in this population. Our aim was to examine the prevalence of aspiration signs in adults with DS.

Methods: Caregiver report of swallowing-related concerns and a water-swallowing screen were used to assess signs of aspiration in 26 community-dwelling adults with DS who were otherwise healthy. Individuals were excluded if they had a pre-existing diagnosis of swallowing dysfunction or an estimated IQ below 25. Signs of aspiration were determined through a caregiver questionnaire and 3 trials of the 3oz water-swallowing test, screening for the following signs: coughing, throat clearing, choking, voice change, or stopping prior to completion.

Results: Only 4 of the 26 participants (15.4%) had no signs of increased aspiration risk during testing. Eighteen participants (69.2%) screened positive during trial 1. Caregivers reported a comparable prevalence, providing converging evidence of high aspiration risk. Comparisons of swallow test results with previous reports for patients with stroke or Parkinson disease indicated comparable or slightly higher rates of positive screenings for adults with DS, despite their being otherwise healthy and considerably younger.

Conclusion: The prevalence of aspiration signs within this cohort of young, otherwise healthy adults with DS was comparable to that of high-risk patients reported elsewhere. Therefore, results support the hypothesis that swallowing dysfunction and aspiration may contribute to risk for the development of pneumonia in this population.

Keywords: Down syndrome; Aspiration; Dysphagia; Pneumonia

Background

The longevity of people with Down syndrome (DS) has improved over the past quarter-century [1,2], but the age-specific risk for mortality is still increased compared to others with intellectual disabilities and to the typically developing population [3]. A major cause of morbidity and mortality in the DS population is respiratory infections leading to chronic pulmonary interstitial changes [4] despite the infrequent occurrence of primary pulmonary disease [5-12]. A recent review revealed that the cause of death is listed as pneumonia for 47% and pneumonia associated with aspiration or choking in 13% of adults with DS [3]. Most bacterial pneumonias (such as those due to the *Pneumococcus* and gram-negative bacilli) are due to aspiration of pharyngeal contents. Infections by airborne droplets (e.g., tuberculosis) or hematogenous spread (some cases of *Staphylococcus aureus*) are less common [13].

In the aging population overall, dysphagia is a major risk factor for pneumonia and a predictor of fatal outcome [14,15]. Complications of swallowing dysfunction and aspiration are not limited to respiratory infections and chronic lung disease, but can also include malnutrition, dehydration, airway obstruction, adult respiratory distress syndrome, abscess formation, pulmonary fibrosis, and death [16]. To our knowledge, the prevalence of swallowing problems in the DS adult population is not known and there is concern that these individuals are at an increased risk. Smith et al. [17] reported coughing, a sign of possible aspiration, in 56.5% of individuals with DS during one meal. Choking has also been reported frequently by caregivers of adults with DS, and "needing help with liquid" was associated with a history of choking [18].

This study examined the prevalence of aspiration signs in adults with DS both directly and through caregiver report. We hypothesized that signs of aspiration would be highly prevalent. A secondary hypothesis was that the caregiver's report of aspiration signs would be consistent with those seen during formal screening.

Sign	Trial 1	Trial 2	Trial 3	All trials	Caregiver report	P-value*
Cough	3 (11%)	2 (8%)	0 (0%)	5 (19%)	13 (50%)	0.02
Choke	1 (4%)	1 (4%)	0 (0%)	2 (8%)	9 (35%)	0.02
Throat clear	2 (8%)	2 (8%)	2 (8%)	4 (15%)	12 (46%)	0.02
Voice change	7 (27%)	2 (8%)	2 (8%)	7 (27%)	7 (27%)	0.9
Stop	17 (65%)	16 (62%)	14 (54%)	20 (77%)	–	–
Failure (overall)	18 (69%)	16 (62%)	15 (58%)	22 (85%)	18 (69%)	0.17

Table 1: Signs of aspiration during 3oz water swallowing trials and as reported by caregivers (n=26)
*All trials vs. caregiver report.

	Positive screen	Negative screen	Total
Positive caregiver report	16	2	18
Negative caregiver report	6	2	8
Total	22	4	26
			P=0.289

Table 2: Caregiver symptom report compared with formal screening, all trials (n=26)

Methods

Participants

Twenty-six healthy, community-dwelling adults with DS aged 18 or older volunteered for the study (All were patients of a co-investigator **Capone G**). Participants were excluded if they had an estimated IQ under 25 or if they had a formal diagnosis of swallowing difficulty. Mean age was 33 years (range: 19-54). In total, 50% were males, and 50% were females.

Procedures

Informed consent was obtained from the participant's legally authorized representative, and assent was obtained from participants. The study was approved by the Johns Hopkins University School of Medicine Institutional Review Board.

Signs of aspiration were determined through a caregiver questionnaire and 3 trials of the 3oz water-swallowing screen [19]. The screen requires drinking 3oz of water and is positive if any of the following signs are observed: coughing, throat clearing, choking, voice change, or stopping before completion. The swallow screening was performed with the participant in a seated position.

Statistical analysis

Presence/absence of each aspiration sign was recorded for each trial. The overall number of adults experiencing at least 1 sign was calculated for each trial, as was the number experiencing each sign across all 3 trials. Each subject was also classified as being at increased aspiration risk by caregivers if any sign of aspiration (cough, choke, throat clearing, and voice change) was reported. Tests of proportions were used to compare aspiration signs by caregiver report and the water swallowing test. McNemar's chi-squared test was used to compare the overall assessment by caregiver report and the screening test. Swallow findings were compared with those reported by Suiter and Leder [20] for patients with left stroke, right stroke, brainstem stroke, and Parkinson's disease (all considered to be at high risk) using Chi squared statistics. Analyses were conducted using intercooled Stata, version 11.2 [20].

Results

Only 4 of 26 participants (15.4%) had no signs of aspiration during swallow testing, and 18 (69.2%) screened positive on trial 1 (An additional 4 adults screened positive on subsequent trials). Trial-by-trial risk signs are summarized in table 1 along with caregiver reports. The proportion of caregivers reporting cough, choke, or throat clearing was higher to that detected during water-swallowing trials. No difference was detected for voice change between the screening test and the caregiver's report. Further analysis suggests that, altogether, a positive report by caregivers (including any sign) is not statistically different from the results of the formal screen (Table 2).

Data reported by Suiter and Leder [20] permitted calculation of positive and negative screen results for 4 high-risk patient groups: (a) left stroke (N=227; positives=63.4%), (b) right stroke (N=203; positives=66.0%), (c) brainstem stroke (N=38; positives=73.7%), and Parkinson disease (N=18, positives=61.1%). Because Suiter and Leder employed only a single trial, these results were compared to trial 1 for the present sample of adults with DS. While prevalence of a positive screen was slightly higher for the DS sample (69.2%) compared with all but the group with brainstem stroke, no differences approached significance (uncorrected chi-square p0.34).

Discussion

Signs of aspiration risk were commonly reported by caregivers and detected with a simple water-swallowing screen. Findings were comparable to those reported for several samples of high-risk patients [20]. The high prevalence of aspiration signs in this population suggests that aspiration might be an important factor contributing to pneumonia risk.

The swallowing screen employed in this study formally assessing the prevalence of aspiration signs in healthy adults with DS is known to have a high false-positive rate [20] thus these findings may over estimate the prevalence of aspiration signs. Nevertheless, caregiver reports were comparable or higher and the overall proportion of positive screens was similar to observations in patients known to have increased aspiration risk. We failed to detect a statistically significant difference between the results of the screening test and the caregiver's report. This suggests that a caregiver's report of aspiration signs should clue the clinician to the need for formal evaluation.

Dysphagia is seen often in infants and young children with DS, likely of anatomical origin and with generalized hypotonicity and esophageal dysfunction as the associated underlying impairments [21-23]. Often, dysfunction has been thought to improve with maturation [24] but the present findings suggest that swallowing-related concerns may persist into adulthood for a significant proportion of this population. Given the high pneumonia-associated mortality rate in this population, standards for clinical surveillance need to be clarified to reduce aspiration-associated morbidity and mortality.

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