



The Development and Implementation of A Data Repository for Swallow Studies

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Abstract

Purpose The purpose of this clinical note is to (a) describe the development of an open-source data repository of videofluoroscopic evaluations of swallow studies (VFSS) from individuals across the lifespan with various feeding and swallowing disorders, and (b) to qualitatively assess the usefulness of a repository to engage students in research in swallowing disorders.

Method This project was divided into two phases. Phase 1 focused on the development of the repository. This entailed identifying videos, removing private information, developing codes for swallow events and bolus variables, transcribing videos, and uploading them to a publicly available site for easy access. Phase 2 assessed the usefulness of the repository as a research tool. In this phase, a group of graduate and undergraduate students investigated a research question of interest to them. Each phase incorporated a qualitative analysis to examine the challenges encountered in that given phase.

Results An open-source data repository of swallow studies, called DysphagiaBank, was successfully developed and uploaded into the TalkBank data repository. The database was easily employed by both graduate and undergraduates to engage in research in a timely fashion. Across qualitative analysis, the single consistent barrier to success was the COVID-19 pandemic that impacted access to campus and adequate internet for streaming.

Conclusion The use of an open-source data repository improved our students abilities to engage in research and enhanced their understanding of swallow physiology across the lifespan.

Introduction

Data repositories sort and organize information collected from a focused population or outcome measure. Repositories have been employed to support research queries and clinical

education [1]. In general, repositories streamline data collection and querying to support efficient knowledge advancement. TalkBank, a web-based collection of data repositories that was initially established in 1984, now contains large language data sets from various populations including, for example, individuals with aphasia, disfluencies, and right hemisphere dysfunction [1–5]. The framework employed in TalkBank is simple—catalog data sets from various institutions and researchers to support open data sharing. In short, access to TalkBank, whose data sets are largely focused on language output, has been successful in advancing knowledge of these language sets as evidenced by, according to Google Scholar, over 4000 publications that have utilized this resource to ask and answer research questions. It is alluring to apply this framework to other data sets, such as swallowing disorders. It is particularly appealing when one considers the challenges to research in the area

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of swallowing disorders, and the ability of a data repository to enhance access to data, thereby increasing research productivity.

The prevalence of disorders of feeding and swallowing has been reported to range from 10% to as high as 60% [6]. To adequately evaluate these disorders, one must employ an instrumental evaluation. The two most used instrumental approaches for evaluation of feeding and swallowing disorders are the radiographic exam (i.e., videofluoroscopic evaluation of swallowing, VFSS); aka, modified barium swallow study) and fiberoptic exam (i.e., flexible endoscopic evaluation of swallowing, FEES). While these instrumental exams are employed clinically in the diagnosis of feeding and swallowing disorders, for some university faculty there is limited access to instrumental exams to support clinical education and research. The reason for this may be simple. Access to instrumental exams, particularly those that employ radiology, are expensive. Even if the technology is available, access to the equipment may be limited for teaching and research given community need and utilization.

We postulate that access to a collection of VFSS videos would enhance both student learning and research productivity. Access to VFSS exams engage the student in the swallow physiology at a higher level, thereby improving their ability to develop critical clinical knowledge and skills for dysphagia management [7]. In fact, as the percent of digital native students increases, there is a noted increase in their positive attitudes towards the use of technology to enhance learning [8]. Yet, for some instructors and students, particularly those that are not affiliated with a medical school, these important teaching resources are not readily available.

Research in swallowing and its disorders is a lengthy process when instrumental data are included. This is particularly true when procedures involve ionizing radiation. In academic master's level programs, students may engage in research (e.g., a Master's thesis). However, with heavy clinical requirements, the ability to complete a research project may be limited to students who can extend the length of their graduate program. This fact often excludes students from participating in research in swallowing disorders. In addition, Institutional Review Board (IRB) approval for projects that employ VFSS often requires review by a radiation safety committee, adding to the institutional approval timeline. Once approved, without funding there is limited access to radiology procedures. Even with funding, scheduling use of the equipment for research purposes may increase data collection timelines due to limited availability of equipment given clinical demand. To improve access to clinically relevant data, other areas of speech-language pathology have employed data repositories to support student research and exploration of essential questions. For example, a repository of language samples from individuals with aphasia is

available on TalkBank and allows students access to critical learning about various aphasic profiles.

We hypothesized that over time a data repository of open-source swallow studies could engage clinicians, educators, and researchers and, through increased understanding of swallow physiology, enhance our knowledge of clinical management for this broad population. As an initial step, the purpose of this clinical note is to (a) describe the development of an open-source data repository of videofluoroscopic evaluations of swallowing from individuals across the lifespan with various feeding and swallowing disorders to be stored with the TalkBank collection, and (b) to qualitatively assess the usefulness of a repository to engage students in research in swallowing disorders.

Methods

This project was divided into two phases. Phase 1 focused on the development of the repository. Phase 2 assessed the usefulness of the repository as a research tool. Each phase incorporated a qualitative analysis to examine the challenges encountered in that given phase.

Repository Development, Storage and Access

Inspired and supported by TalkBank, we developed a repository of swallow studies. Development of the repository included (a) identification of completed studies, (b) medical record review to extract pertinent data for each identified study, (c) scrubbing swallow videos to remove private information, (d) development of swallow-specific codes to aid in consistent and thorough transcription, (e) training the research team in the scrubbing process and codes used for transcription, (f) transcription of each video, and (g) transportation of videos and associated transcripts to the web-based repository system. The inclusion criterion for VFSS was that the study had been collected using 30 frames and 30 pulses per second. There were no exclusion criteria. All studies included in the database were acquired for clinical purposes. Although some studies demonstrate minimal to no deficits, it is difficult to state that these are "normal" as they were acquired from individuals who were referred for a swallow study and/or reported symptoms of dysphagia.

Video acquisition. Using a digital imaging software that supports both archiving and editing (TIMS MVP and TIMS review software; www.tims.com) previously collected videofluoroscopic swallow studies were acquired for this project.

Medical record review. In compliance with IRB requirements, specific individuals were granted permission to

Table 1 Data points extracted from medical records

• Medical diagnosis(es) –When multiple diagnoses were present, we identified the one(s) linked to referral for a swallow exam
• Age at onset of diagnosis
• Age at time of video
• Current diet

extract data from medical records. Commonly extracted data points are listed in Table 1.

Scrubbing videos. Identified VFSS were reviewed in the TIMS review software to locate (a) unnecessary video clips, and (b) private information revealed during the study either through the video or audio data. With a goal of keeping videos small for optimal streaming, clips were identified as unnecessary, and removed from the video, if they did not contain any swallow attempts and there was no bolus in the image. Using three checkpoints to ensure that secure or private data was not released into the open-source repository, private information was redacted from the images. The three checkpoints were (1) when the video was first exported out of TIMS, (2) during transcription of the video, and (3) after transcription was completed and before being uploaded onto the TalkBank system. At each time point, if private information was identified either in the audio or video feed, the video was sent back for trimming (which can be completed in TIMS MVP) to remove private information. Private information in the audio feed often included the name of the patient or clinician; in the video feed, medical record number or patient name was at times included in the early section of the video.

Code development and transcription. An important tenet of TalkBank is the use of a consistent coding schema for each repository in the collection. Swallow videos contained both spoken events and swallow events. While TalkBank has well-developed codes for speech, there were no existing codes for swallow events. We set to build an analytic framework to match the needs of the topic area. Swallow-related codes were divided into subsets—viscosity, volume, presentation, compensatory strategy, and response. Viscosity and volume codes were used to identify characteristics of the bolus. Presentation codes identify the bolus presentation format (e.g., the bolus was presented via cup, spoon, or bottle). Specific presentation codes were developed to provide details regarding the type of cup (e.g., sippy cup, nosey cup), bottle (e.g., Avent stage 12), or nipple (e.g., medium flow). Compensatory strategy codes were used to indicate if a specific maneuver or posture was being employed during a given swallow. Response codes identified the observable presence of a reaction to a given bolus (e.g., cough).

Codes were developed using an iterative process which started with a proposed list of codes for each of the identified categories. When an event or bolus characteristic was

Table 2 Sample codes

	Description	Code
Volume	5 mL	5ml
Viscosity	Thin liquid/water	0
	Burrito	7
	Rice cereal	RC
Presentation	Nipple- Brown's Level/Stage 1	B1
	Nosey cup	NC
Compensatory	Chin tuck	CHT
	Effortful swallow	ES
Reaction	Throat clear	TC
	Cough	cough

identified that had not been previously used, a new code was entered into the system, and previously transcribed studies were reviewed for any application of the new code. This was done for a minimum of 20 studies that included a mix of both pediatric and adult videos. Table 2 displays a sample of these codes. Once codes were clarified, all videos were transcribed using the CHAT format [9]. Videos and transcriptions were uploaded to the TalkBank collection and stored under the AphasiaBank.

Repository Engagement

Three students (two undergraduate and one graduate) were recruited to complete a student-selected research project using the repository data. All students completed MBSImP training and reviewed the penetration-aspiration scale (Pen-Asp) [10, 11]. Students scored a subset of videos until they were reliable with the PI. Students individually analyzed VFSS from the repository set. Across the three students who were on the research team, when disagreement occurred in any rating, a consensus procedure was employed.

Qualitative Analysis

Guided by a set of predetermined questions, two semi-structured group interviews were conducted (Table 3). The first interview was conducted with the members of the data collection and analysis team after 50 swallow studies had been collected and coded. The second interview was conducted with members of the repository engagement team upon completion of the research project. Using the starting probes noted in Table 3, team members were guided to discuss challenges faced in different phases of the project. Follow up questions were determined based on the participants' response to the initial questions. The group interview was moderated by the first author in the lab setting where most of the repository development and engagement activities occurred. A non-standard analysis approach was used whereby themes and subthemes were identified while the focus group discussed the challenges of the project. Upon

Table 3 Starter prompts employed for focus group discussions

Repository Development	<ul style="list-style-type: none"> • Describe any challenges in the development of the repository. • Consider all aspects of the development including extraction from TIMS, coding, formatting, privacy checking, TalkBank compliance checking, and share those areas that presented the greatest challenge. • Provide specific examples of when you faced a challenge with development of the repository.
Repository Engagement	<ul style="list-style-type: none"> • Describe any challenges in research. • Describe challenges specific to using the repository of swallow studies to answer the research question. • Provide specific examples of when you faced a challenge when using (or trying to use) the repository.

Table 4 Information to access the open source DysphagiaBank.

Link	https://aphasia.talkbank.org/access/English/Other/Dysphagia/UNM-access/UNM.html
Navigation	<ul style="list-style-type: none"> • Start at www.Talkbank.org. • Choose <i>AphasiaBank</i> • Choose <i>Non-Protocol English</i> • Choose <i>Dysphagia</i>

Table 5 Participant data from first 73 studies included in the repository

Age (years)	n	Diagnostic category			
		General Medical	Neuro	HNCa	Other
0–3	30	0	0	0	30
4–18	3	0	0	0	3
19–50	7	1	2	1	3
51–75	15	4	1	1	9
76+	18	1	5	1	11

completion of the discussion, written notes obtained from the discussion were presented to the group to seek verification and details about each of the identified theme areas.

Results

Repository Development, Storage, and Access

Swallow codes were developed using an iterative process. Codes are now available that can be employed in future database entries. A repository of swallow studies was successfully developed. DysphagiaBank now serves as an open-source repository database through TalkBank. The Internet location is noted in Table 4. At time of publication 73 studies were included in the repository. Participant data for the first 73 studies are summarized in Table 5. Output includes the video exam along with the video transcription of spoken and swallow events. A sample output is shown in Fig. 1.

Repository Engagement

Three students (two undergraduates and one graduate student) identified a question of interest to them in their development of knowledge and skills in the area of swallowing disorders. They employed the repository to address the relationship between MBSImP scores [10] and Pen-Asp scores

[11]. The Pen-Asp scale is an 8-point scale that codes the presence or absence of penetration or aspiration of material into the larynx. The point system addresses both the depth that material enters the airway and the response to that bolus, where depth is rated with a higher score than ejection. The students hypothesized that MBSImP scores would more tightly correlate with Pen-Asp scores if the Pen-Asp scale was modified to prioritize ejection as opposed to depth of penetrated or aspirated material. Twenty adult swallow studies were selected from the repository to be included in the investigation. For each participant, each rater individually scored the MBSImP and Pen-Asp. Correlations were used to compare the two groups—MBSImP with the Pen-Asp original scoring system, and MBSImP with the Pen-Asp modified scoring system.

Having access to the DysphagiaBank repository made it possible for students to complete this study within one semester. The repository eliminated the need for IRB and radiation committee approval as there are no identifiable data contained within the repository.

Qualitative Analysis

Both graduate and undergraduate students were engaged to develop and employ the repository. Using focus group discussion, the challenges to repository development were categorized into the following themes: technical, privacy and security, code development, and the impact of the COVID-19 pandemic on processes. For use of the repository for research, two themes emerged—training and the impact of the global pandemic. Table 6 provides context on the concerns associated with the various themes.

Discussion

The purpose of this investigation was to develop an open-source data repository that could be used by clinicians (e.g., student, clinical fellows, and experienced clinicians) and researchers to enhance learning, patient education, and research. At time of this publication, we were able to identify and code 73 swallow studies and upload them onto the TalkBank collection site. The data are readily available to the public.

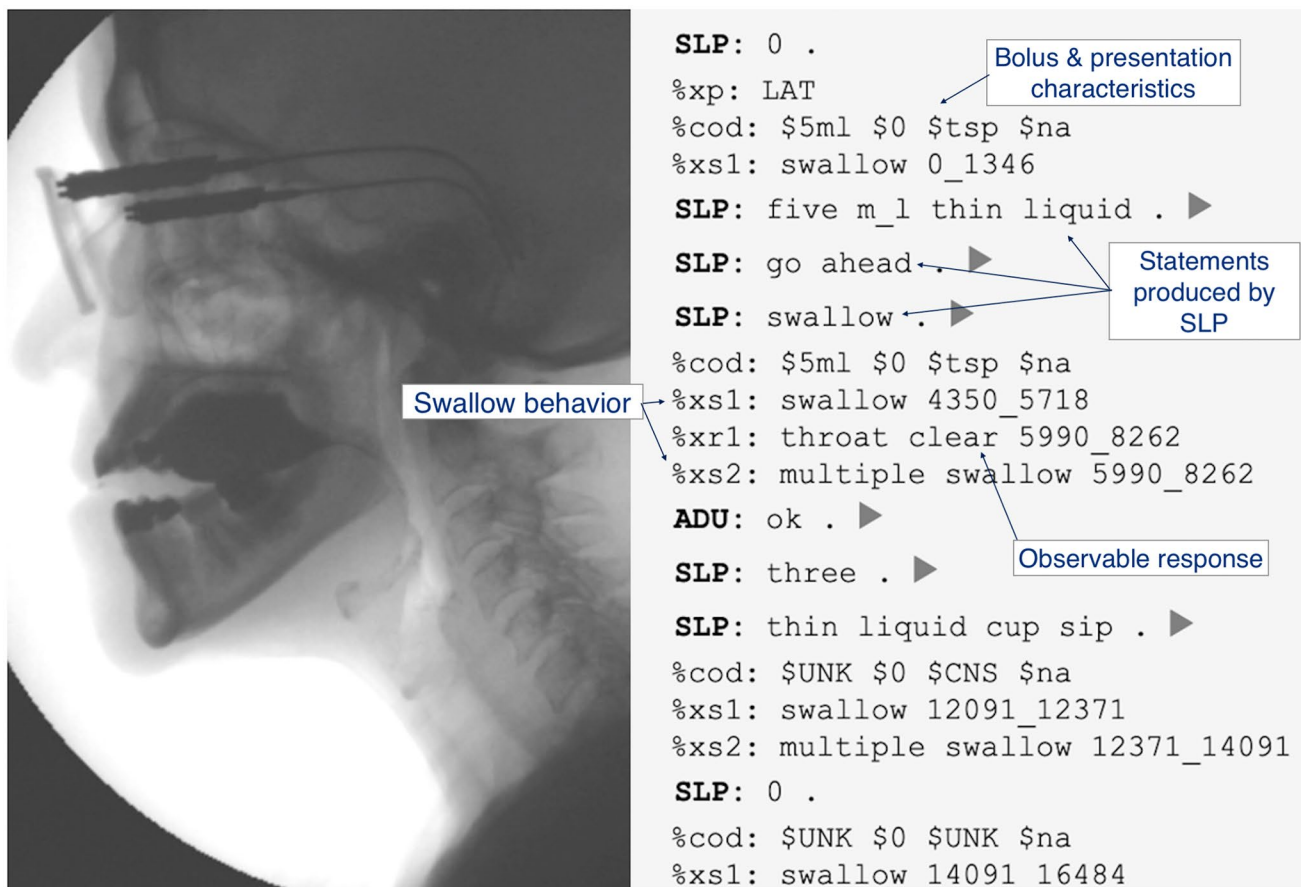


Fig. 1 A sample screen shot from the repository database that shows the video image on the left and the transcription code on the right

During focus group discussion to identify challenges associated with repository development and repository engagement, one consistent theme was reported—the impact of the COVID-19 pandemic. In the early phases of the pandemic, the University limited access to buildings and limited the number of people in each lab at one time. With reduced hours on campus, students had limited access to VFSS data and the required software for preparing and transcribing videos. With limited access, students reported challenges in learning and maintaining the procedural steps used to clip, concatenate, download, and transcribe videos. To make this process available to be completed off campus, we trialed the use of a Microsoft SharePoint site for videos in need of transcription. This presented another challenge, as students had inconsistent access to adequate Internet to stream the videos stored on the site. Also, some students had reduced availability to work on the project due to personal illness or their caregiver duties for ill family members.

Technical difficulties were expressed as the most frustrating component of the database development process. Coding challenges may be explained by the fact that most of this project was completed by graduate students studying to become speech-language pathologists; none had previous

coding experience. Several months were dedicated to finding the balance between identifying a video format that was compatible for streaming in TalkBank yet retained sufficient resolution to support accurate clinical interpretation. Further, for use in research the greatest technical challenge in using the DysphagiaBank was the lack of online frame-by-frame analysis, which can be used to support swallow analysis, and is a capability not currently available in the TalkBank system. However, TalkBank does support media download. Once downloaded, the media can be viewed using other viewers that support frame by frame analysis.

The repository was successful in supporting ease in student research. Even with the challenges identified in the focus group discussions, the use of a deidentified database allowed for the completion of a research project aimed at exploring an aspect of swallow disorders. As the database is publicly available and contains no private health information, no IRB approval was required. By eliminating the need for institutional review, the project was conceptualized, implemented and completed within a single semester. In the case of swallowing disorders where swallow studies involve ionizing radiation, the ability to bypass human subject review since the database is publicly available

Table 6 Summary of themes and subthemes identified in the qualitative analysis from (a) repository development and (b) repository engagement

Themes	Subthemes	Description
Phase 1: Repository Development		
Technical	Video formats	Identifying a format that allowed for high resolution, ease in streaming, reduced storage space, and compatibility with TalkBank
	Resolution vs. speed	To successfully use the repository, we had to consider which variable would be most important to researchers and clinicians—streaming speed or resolution.
Privacy & Security	Deidentification (audio & video)	Challenge in catching all incidences of personal or private health information. Due to the random nature of PHI placement multiple checks were required. (a) The acquisition software resulted in individual frames with PHI that were randomly distributed throughout the video. (b) During acquisition, names were used and recorded into the audio stream.
	Data loss	At times, to remove PHI, a section of the video had to be removed or the video and audio required separate splicing. This sometimes resulted in the loss of swallow data.
Coding	Development process	The iterative approach required that videos underwent repeat transcriptions when a new scenario was identified. This slowed down the progress and coders reported being frustrated.
Global Pandemic	Reduced patient care	Less instrumental exams were being performed as hospitals were limited to urgently-needed procedures which reduced the available dataset.
	Reduced lab access	Lab occupancy was limited by the university which limited students working together.
Phase 2: Repository Engagement		
Training	VFSS	Students required training in reading and interpreting videofluoroscopic studies. Without frame-by-frame viewing, interpretation was sometimes challenging, especially in infant studies.
	Repository interface	(a) Students required training in use of the repository interface. This could not be done in a group format due to restrictions placed by the global pandemic. (b) The interface did not work well on smart devices such as iPhone.
	Codes	Students had to develop familiarity with available codes to interpret the transcription.
Global Pandemic	Student availability	Many students went home during the pandemic and were caring for sick family members or were sick themselves.
	Reduced lab access	Lab occupancy was limited by the university which limited students access to the repository if they did not have adequate internet access.
	Unreliable internet	Students did not have access to high-speed internet to support streaming off campus and campus access was limited. Students often needed to come to campus to complete the activities and lab access was limited due to the pandemic.

and contains de-identified data only, may greatly improve research yield. Also, participation in research or engagement with repository data may improve student understanding of swallow physiology.

While the benefits of the repository of swallow studies are easily identified, there are some limitations. The TalkBank software has traditionally been used to document speech and language. Therefore, the software is geared to audio. One example of this is the replay function. All speech segments are linked to a time code and can be individually selected for replay from the transcript. When an event occurs without speech, there is no replay function in the transcript. Note in Fig. 2, a clip from a transcript, there are times when an individual is provided with a bolus and no speech occurs during the recorded clip. These are indicated as “SLP: 0.”.

This allows us to link the swallow event to a time code, but because no speech segment is associated with the swallow event, it cannot be selected for replay from the designated time code. Notably, now that it has been identified, this limitation can be removed with TalkBank programming.

Another limitation of the TalkBank system is the lack of a frame-by-frame video replay function. This function is helpful, particularly for those learning how to read videofluoroscopic exams, and in fact, frame-by-frame analysis is recommended [12]. Although there is a work around, it involves downloading the video from the TalkBank system. An ideal solution would allow the reviewer to navigate frame by frame within the online repository.

The qualitative analysis may be limited due to the use of written notes as opposed to recorded and transcribed interactions.

Fig. 2 An enlarged clip from a specific transcript. Each number on the left relates to a new bolus presentation. When a line ends in a triangle that indicates that the video can be queued and played from that specific location. Note that not all swallows can be played through this process. When swallows are not linked to spoken text, the time-code play-back function (triangle) is not added to the transcript. *Note: SLP indicates what the SLP said; CHI indicates what the child said; MOT indicates what the mother said; xp indicates position codes; xs indicates a swallow event; xr indicates a response to a swallow*

```

1  SLP: 0.
   %xp: LAT
2  SLP: it's like milk thin liquid . ▶
   %cod: $UNK $0 $CNS $na
   %xs1: swallow 1917_6324
3  SLP: good job . ▶
4  SLP: thin liquid . ▶
   %cod: $UNK $0 $CNS $na
   %xs1: swallow 10510_12598
5  SLP: good . ▶
6  SLP: thin liquid straw . ▶
   %cod: $UNK $0 $STR $na
   %xs1: swallow 16230_17286
7  SLP: good . ▶
8  CHI: mommy . ▶
9  SLP: take one more . ▶
   %xs2: multiple swallow 23094_23880
10 MOT: there you go . ▶
11 SLP: thin straw . ▶
   %cod: $UNK $0 $STR $na
   %xs1: swallow 30240_31760
12 MOT: good . ▶
13 SLP: good pudding . ▶
   %cod: $UNK $3 $UNK $na
   %xs1: swallow 38240_40080
14 CHI: xxx . ▶
   %cod: $UNK $3 $UNK $na
   %xs1: swallow 45720_52304
15 CHI: mom . ▶
16 SLP: xxx clearing . ▶
   %xs2: multiple swallow 57247_58495
   %xr1: throat clear 58495_59152
17 MOT: there you go . ▶
18 SLP: good job . ▶

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Although the authors feel that the qualitative analysis completed in this investigation reflects the challenges faced by the development and engagement teams, future studies should utilize standard qualitative analysis procedures including transcribed interviews. It is possible that if transcription had been included in this study, then additional themes may have been identified.

Future Plans

The repository will be enhanced through growth and diversification. Ideally, this database will incorporate “healthy” or “normal” swallows with distribution across the age range from infants to adults. However, at this time, the retrospective nature of this database limits the selection to those individuals who were referred for a swallow study. We seek to obtain swallow studies from a variety of facilities and instrumented approaches including FEES and high-resolution manometry. The limitations of the repository playback will be explored to note the feasibility of adding frame by frame analysis and a timecode-based playback that links to swallow actions instead of speech events.

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Declarations

Conflict of Interest Author A declares that she has no conflicts. Author B declared that he has no conflicts. Author C is one of the original developers of the TalkBank repository. He did not receive any funding to support the addition of the swallow database into the TalkBank repository.

Ethical approval No animals were used in this study. Human data involved retrospective data that was collected for clinical purposes. All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was waived.

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