

TITLE PAGE

Helping patients with head and neck cancer understand dysphagia: Exploring the use of video-animation

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Abstract

Purpose: Patients newly diagnosed with head and neck cancer should be informed of the ramifications of cancer treatment on swallowing function during their pre-treatment consultation. The purpose of this study was to explore 1) the usefulness and 2) the acceptability of video-animation in helping patients to understand the basics of the swallowing mechanism, and dysphagia.

Method: Thirteen patients treated for HNC participated in this study. Think-aloud, a type of qualitative methodology was used to encourage patients to verbalize their thoughts while watching two short video-animations showing the process of normal/abnormal swallowing. Transcripts were analyzed using thematic analysis.

Results: Four main themes were identified. 1) patient interest and engagement, 2) acceptability of visual imagery and narration, 3) information provision and learning, 4) personal relevance and intended action. Patients appeared interested and engaged in the video-animations, asking several spontaneous questions about how to maintain or improve swallowing function. Learning was evident from patients' recognition and verbalizations of grossly disordered swallowing patterns. Most patients reported the images to be visually acceptable, and could often relate what they were seeing to their own swallowing experience. Many patients also verbalized recognition of the need to keep muscles active through exercises.

Conclusions: These results suggest that the video-animations of swallowing were acceptable, interesting, informative, and relevant for most patients. It was therefore

useful not only as an education tool, but also showed potential to influence patients' intentions to undertake preventative interventions that may preserve better swallowing function after cancer treatment.

Helping patients with head and neck cancer understand dysphagia: Exploring the use of video-animation.

Background

Dysphagia affects the majority of patients undergoing treatment for head and neck cancer (Wall, Ward, Cartmill & Hill, 2013). Newly diagnosed patients are generally provided with information about the ramifications of their disease and treatment on swallowing function as part of the process of informed consent for cancer treatment (Clarke et al., 2016; Collins, Flynn, Melville, Richardson & Eastwood, 2005; Patterson & Wilson, 2011). We postulated that this information provision could provide an opportunity for patient education that extends beyond the mandated requirements of informed consent to treatment. Through the use of a different medium (video-animation), information could be purposefully conveyed to increase patient understanding of the swallowing process, thereby promoting likelihood of better engagement with early swallowing interventions.

The theoretical basis for the present study is drawn from the Common-Sense Model of Self-Regulation (Leventhal, Brissette & Leventhal, 2003; Leventhal, Phillips & Burns, 2016). Based on his early empirical work, Leventhal (1980) proposed that

individuals process information about illness or any threat to health via parallel channels representing cognitive and emotional dimensions. The Common-Sense Model suggests that individuals who are faced with a health threat (in this case, dysphagia after head and neck cancer) develop mental images about this threat based on five main dimensions: 1) *identity* [illness label, symptoms], 2) *cause* [infection, hereditary, lifestyle], 3) *timeline* [age of onset, expected duration], 4) *consequences* [pain, impact on functioning, QOL], 5) *controllability* [perception of cure or control] (Leventhal et al., 2003). Messages presented in a concrete and experiential format illustrating the likely threat could drive an individual's motivation to take action to alleviate the threat and thus influence future health behaviours (Leventhal, 1965; Leventhal, 1971; Leventhal & Cameron, 1987). Applying this model (see Figure 1) to patients with head and neck cancer, it can be seen that messages provided by clinicians may be perceived and processed via both cognitive and emotional channels which inform perceptions about the threat or *danger* (dysphagia after cancer) as well as worry and *fear* (never eat again). Both, patients who do not perceive any threat (for example those who do not believe that their swallowing will be affected) and those who become "paralyzed" by fear may likewise be disinclined to engage in any preventative behaviour such as prophylactic exercises. Understanding more about how patients process and perceive the messages we provide may be crucial to ensuring their engagement with preventative interventions and longer-term rehabilitation.

[insert Figure 1 here]

Drawing on the above theory, we posited that video-animation could offer a readily available and practical way for representing swallowing in a more concrete format

compared with verbal or written explanations and pictorial representations.

Animation is useful to communicate effectively with patients of differing levels of literacy skills (Meppelink, Van Weert, Haven, & Smit, 2015). Video-animation also has the potential to relay sequential and dynamic information relatively quickly. This medium may therefore be better for depicting a complex process such as swallowing than written or verbal information alone that may fail to achieve the same clarity (Wilson & Wolf, 2009).

To our knowledge, there are no published studies that have specifically assessed the use of video-animation in providing head and neck cancer patients with information about the process of normal swallowing at any stage of their care. However, video-animations have been used successfully for patient education in other health domains (Nakagami-Yamaguchi et al., 2016; Leiner, Handal & Williams, 2004; Ferguson, 2012). In one study on educating patients about periodontal disease (Cleeren, Quirynen, Ozcelik, & Teughels, 2014), the authors found that recall and retention of knowledge was better in the group of individuals randomized to receive information about periodontitis via a 3D animation video compared with the control group who received the same information presented via picture sketches typically used during a dental consultation. The above studies demonstrate that video-animation can be more effective in improving patient knowledge relative to other methods such as print materials, although animation will require individual testing for different target populations and disease conditions (Wilson et al., 2012). Whilst we have a good theoretical basis for this study, it was prudent to first establish preliminary information about the use and acceptability of video-animation in discussing dysphagia with the target patient group prior to incorporating this into the “live” pre-

treatment consultation for individuals newly diagnosed with head and neck cancer. Thus in the present study, the aim was to use qualitative methodology to broadly explore whether video-animations of normal/abnormal swallowing was useful (potential to improve knowledge and understanding, and intention to engage in preventative interventions) and acceptable to patients who completed treatment for head and neck cancer.

Methods

This study was part of a broader qualitative study examining head and neck cancer patients' views about swallowing pre/rehabilitation, results of which have been previously reported (Govender et al., 2017). Whilst the same sample was drawn upon, the research aim and method for the present study is distinct from the previously reported interviews. Consent was obtained simultaneously for both studies prior to the interview. Further information about the characteristics of patients recruited to the study is presented in Table 1. The overall project received full approval from a National Health Service ethics committee [14/ LO/1152].

[insert Table 1 about here]

Study design – brief overview of think-aloud method

Think-aloud is a recognized method in qualitative research (Charters, 2003), based primarily on human information processing theory and related work by Ericsson & Simon (1980). Typically, participants are asked to verbalize their thoughts (putting into words their actions, feelings, thinking) during a task, and/or immediately after. Asking individuals to think aloud whilst engaging in a task draws upon short-term

(working) memory and provides a window into the cognitive processes taking place during the task (Ericsson & Simon, 1980). Due to the immediacy of the responses, researchers may be better able to capture the full nuances of *actual experience* rather than relying solely on patient recall. This approach may offer new insights about how information is perceived and processed. The primary attribute of this method is the verbal data generated from thinking aloud, but exact protocols may differ depending on the nature of the research question and task (Kuusela & Paul, 2000). In this study, we used a hybrid approach whereby patients were encouraged to verbalize their thoughts during a task (concurrent think-aloud). Comments made immediately after the task (but within the recorded interview timeframe) were also included within the dataset and may represent some reflective thinking (Kuusela & Paul, 2009).

Study materials and procedure

The video-animation used was developed by Northern Speech Services, USA (www.NorthernSpeech.com) as part of an online training tool that was subsequently modified for a Dysphagia App (Fig 2 - see video still). The video-animated images were based on those seen during a modified barium swallow or x-ray swallow, except that the images are more realistic than conventional x-ray images of swallowing. Two videos were played in succession; one depicted a normal swallow and the other a typical post radiotherapy swallow showing increased swallowing effort, pharyngeal residue and repeated attempts to swallow the same bolus (disordered swallow). The videos were played on a laptop computer, initially at normal speed to demonstrate the swiftness of swallowing and then at half speed. All patients were first shown a static image that was used to orientate the patient and point out the key anatomical structures involved in swallowing such as the tongue,

palate and larynx. The video images showed a lateral profile of the head and neck so that key structures and their action during swallowing could be identified. The videos were less than a minute in duration. However, the speed at which they were played could be reduced in order for the process of swallowing to be viewed more slowly.

Patients were informed that the researcher would show two short videos explaining the process of swallowing during the first video. The researcher provided a verbal overview of the key steps in the process of normal swallowing to each patient. This method was chosen instead of an audio voice-over to allow for modification in pacing and a degree of flexibility. Salient aspects of the normal swallowing process were highlighted using the pause button; for example, the researcher pointed out how the larynx moves upward and forward to prevent liquid entering the airway. The disordered swallow animation (second video) was played immediately after without narration.

Patients were asked to verbalize their thoughts during the viewing of the second video. They were told that they could request to view the video repeatedly if required, and that the researcher would like them to keep talking aloud their thoughts. They were advised that the researcher was interested in whatever they thought about the video-animation and images, what they were seeing and what thoughts or questions were going through their mind. Patients were also informed that the researcher preferred to be quiet during this time but wanted to “hear their thinking.” Minimal prompting such as *“tell me what you thinking”* was used when necessary to encourage talking aloud. If clarification from the patient was required, the researcher repeated the patient’s own words in a question form (rising intonation) thereby eliciting elaboration by the patient.

Due to the short duration of the video-animation, we anticipated that patients would also make related comments immediately after watching the video. These comments were included in the dataset for this think-aloud study. Responses were audio recorded and transcribed verbatim for analysis.

[Insert Fig 2 about here].

Analysis

The data were analyzed using the six key stages of thematic analysis described by Braun & Clarke (2006). These are: 1) familiarity with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, 6) producing the report (p.87).

Transcripts of the recordings were imported into NVivo 10 for Mac (www.qsrinternational.com), a software programme that facilitates the analysis of qualitative textual data. In order to gain familiarity with the data, the text was read repeatedly to obtain an overview of content. The primary researcher (RG) generated the initial codes to describe a meaning unit or basic idea of interest relevant to the study purpose. These were iteratively reviewed and revised as further transcripts were coded. Final codes were then grouped into categories that reflected broader patterns from which themes were derived. These themes were then reviewed in relation to the research aim and the dataset. Closely related themes were collapsed particularly where this provided cogent answers to satisfy the research aims. As the analysis was focused at a semantic level, the themes were identified directly from what patients had said with no attempt to search for underlying meanings.

Interpretation by the researcher was therefore based on the “surface meanings of the data” (Braun & Clarke, 2006 p. 84).

Multiple methods of demonstrating trustworthiness in qualitative results exist, including asking interviewees/participants to comment on results to verify intended meaning (Birt, Scott, Cavers, Campbell, & Walter, 2016). However, using an external group to verify data is thought to be a more useful form of respondent validation (Birt et al, 2016; Morse, 2015). We invited our Public-Patient Involvement group (PPI) to review our preliminary analysis as a way of ensuring that data interpretation was moderated for researcher bias and that the themes were broadly reflective of the patient experience. The PPI group was made up of individuals who have been advisers to the larger intervention development project and were therefore well placed to perform this role. The main themes identified were discussed and agreed between the researcher and two lay public representatives of the PPI group.

Results

Four main themes were identified: patient engagement and interest, acceptability of visual imagery and narration, information provision and learning, personal relevance and intended action. An illustration of how the coding was undertaken is provided in Appendix 1.

Patient Engagement and Interest

All patients demonstrated interest when viewing the first video, making statements such as “*That’s pretty amazing!*” (P13, female) and “*How clever, can I see it*

again?” (P7, male). There was also evidence of active engagement. Patients proactively sought information and asked relevant questions, indicating curiosity and desire to clearly understand what they were seeing.

Is that the bit that’s really important [pointing to tongue base] where it hits the back of your throat? [...] So the tongue becomes weak. What is the exercise for the tongue then? (P10, male).

This is the part that hurts, isn’t it, when it [bolus] goes through here? What’s this one here? (P4, male).

In the absence of a narration accompanying the video of the disordered swallow, most patients either spoke aloud the questions in their mind or provided their own commentary allowing insight into how they processed the information. Patients seemed to have grasped the basic sequence of a normal swallow and many were able to recognize abnormal features evident on the disordered swallow. For several patients, the video offered the opportunity to raise questions about consequences of a disordered swallow using a visual referent. This appeared helpful particularly where patients were unfamiliar with or could not recall the specific terminology.

It’s all coming in here and going down there [pointing to airway]. It [bolus] should be going down there [pointing to oesophagus]. But that [pointing to epiglottis] is presumably, not closing that [pointing to airway] off. And it’s all clustering here. Isn’t pushing into the throat. They try and it doesn’t actually work (P9, female).

It’s [animation] not swallowing, is it? [viewing repeated efforts to swallow, presence of residue] (P4, male).

The stuff [liquid bolus] is stuck behind here, isn’t it? It hasn’t closed up properly. (P12, male).

Is that when you choke when it goes in there? [pointing to airway] So what happens if it [liquid bolus] sticks there? (P7, male).

Acceptability of visual imagery and narration

The video was useful, but patients needed to watch the swallow animation multiple times for the content to be fully appreciated. On presentation of the first video-animation, patients seemed to concentrate intently on the image. Sometimes patients indicated that they were uncertain what to focus on until the researcher provided an orientation to the image (“*Which bit am I supposed to be looking at?*” ; P1, male), or requests to repeat (“*If you could show it a few times and then I would have time to catch up with it and work out what’s going on?*”; P9, female). Showing the initial animation in real time appeared challenging for patients to comprehend (“*That plays too quick?*”; P12, male). Repetition appeared important for comprehension:

Make sure that you repeat it a few times, because people have got so much to take in and sometimes it goes past. They hear it, but they don’t take much notice (P11, female).

Slowing the video to at least half speed and providing salient information about key aspects of the swallowing process seemed to aid understanding.

Participants verbalized the importance of explaining the concepts in plain English as the information was new and complex to most people.

I did A-Level Biology, so I know all the bits and stuff. But probably many people wouldn’t (P12, male).

There were some differences of opinion about the visual acceptability of the images. The majority of patients found the video images acceptable, especially when provided with verbal explanations.

I think the image is fine. It's not anything that... It looks like a standard, sort of, x-ray image. It isn't anything that's gory or anything like that (P3, male).

However, one patient felt that the image was too medical and suggested that a more normal picture of a person eating should be presented first. This "normal picture" could be followed by introducing the idea of looking at what happens inside the mouth by viewing a cross sectional image.

It's medical, it's anatomical, it's scary. There's a lot to absorb. I've seen pictures before, and therefore I sort of can work out a bit what's there. But it did take me several goes (P2, female).

All patients were positive about the video medium and appreciated the dynamic aspect of being able to see what happens during the process of swallowing. One patient compared the task of viewing the video-animation with his own previous experience of receiving a leaflet with a diagram.

I just got a photocopy of the diagram thing [referring to how information about swallowing was provided during his own pre-treatment counseling]. It's much clearer, what's going on, when you can see it from a proper video of it (P6, male).

Information Provision and Learning

Immediately after watching the videos, most patients expanded on their views about the experience with little need for prompting. All patients indicated that the video served a useful purpose in providing information about swallowing and what may go wrong, and that the medium supported their understanding of a process they might not have consciously thought about previously. Patients seemed to reflect on their own experience of being informed about swallowing problems and other side effects

of treatment. Most alluded to the difficulty in actually imagining what this would mean for them.

I think in the beginning you don't really know. People say you might not be able to swallow and you are not going to have any saliva and things like that, and you can't really imagine what that's going to be like. You think, well, I've swallowed all my life, how difficult can it be? You ain't going to forget that (P6, male).

Well, I know about it now, but at the very start I wouldn't have known about it and about what the sensations were going to be. It [the video] shows you... It explains to you what the throat is like, that does, and where the food goes and how it goes down (P4, male).

There was also an indication that patients were processing the information from the video sufficiently well to allow them to identify possible treatment ramifications for themselves.

You just feel your swallow, but you don't see. But seeing if it's moving and what they [muscles] do to make it go the right way, it makes you realise if you don't keep it active all the time and it stops moving then you are going to get really bad problems when it goes the wrong way. You start choking. And that's going to put you off swallowing (P11, female).

Patients were therefore more active learners as opposed to passively listening to the clinician informing them about likely side effects. One patient in particular highlighted this point by making a comparison to her own pre-treatment counselling.

They gave me exercises and like, "That's going to help your swallow," But, for me, I take it all in more when I see stuff. Definitely. That's just the kind of learner I am (P13, female).

Most patients endorsed the idea of using the video-animation before treatment, feeling that this medium would be particularly useful in helping patients understand the need to do their swallowing exercises.

It's a good idea. It's a nice way of helping people understand. It's not massively technical, yes, which is great, but you can illustrate why – 'Look, your tongue is not getting to the back of your throat, therefore with swallowing it's not going to go down. If we strengthen it by biting your tongue and trying to get you to swallow [masako exercise], we will make the tongue stronger as it tries to reach, yes, and you will benefit from that later on.' (P8, male).

And when you see things like that, you do realise you can't take everything for granted and you do need to keep them exercised (P11, female).

Others felt that the visual information might have encouraged them to do their exercises at the early stages.

If this was shown earlier, I would have taken it more seriously (P10, male).

If somebody had explained that to me at the start, I probably would have went for it all, like. But at the time, I didn't know anything about exercises (P4, male).

Personal relevance and intended action

Several respondents seemed to identify with the video of the abnormal swallow, indicating a relevance to their own experience.

That's how I feel. I feel it gets stuck there. I would say mine takes even longer to go down. (P3, male).

Yes, that's what I tend to do [repeated swallows], because I get stuff stuck between my tongue and the epiglottis, and that's where the washing it down with the fluid comes from. Not quite as bad as that, where it's endangering [referring to risk of aspiration]... going the wrong way (P8, male).

Although all respondents had previously received swallowing rehabilitation, the video was clearly helpful in improving their understanding of the swallowing

mechanism, potentially strengthening their intention to carry out post-treatment swallowing rehabilitation exercises.

And even now, looking at that, I think, gosh, I could benefit from those exercises now, because it's something I recognise in possibly the technique that I use to swallow now. Very interesting (P5, male).

Discussion

This study used think-aloud methods to gather patient feedback on an educational video-animation depicting the process of swallowing. The theoretical underpinning for this study is based on Leventhal's large body of work (summarized earlier) relating to patients faced with a new "health threat". Given the exploratory nature of our study, we elected to first gather preliminary information from a group of patients from the target population but who were not newly diagnosed. Results indicated that patients found the video-animation interesting and informative in aiding their understanding of the swallowing mechanism. The swallow animations instigated curiosity and provided the opportunity for patients to clarify their understanding without the need to refer to technical vocabulary. In this respect, video-animation appeared to facilitate patient interaction by removing the need to recall names of anatomical structures or to be concerned with correctly phrasing questions.

Understanding was possibly enhanced by patients focusing more on the visual process of swallowing depicted in the animation. This is plausible given that many patients seemed able to identify where components of the swallow were abnormal despite being given only a brief overview of a normal swallow pattern. The recognition of something being abnormal often triggered spontaneous enquiry of how the problem could be prevented or improved.

Patients' views were largely positive and favourable toward the video-animation used suggesting good acceptability for its clinical use. All patients showed interest and willingness to watch the video. Despite the initial observation that the image seemed too complex, later responses suggested that patients preferred the video medium compared to written information and diagrams or verbal information alone. Slowing down the speed of the video and providing relevant narration seemed to demystify the image. Active engagement was evident from the spontaneous commentary, pro-active questioning and information seeking demonstrated by most patients during the task.

The aim in undertaking this study was to obtain "live" patient responses about the acceptability and usefulness of the video-animation in conveying information about the swallowing process. Swallowing is a subconscious activity that needs to be brought into conscious awareness when discussing the potential impact of cancer treatment on function. The present study was not designed to evaluate different presentation formats. However, these results certainly pose the question of whether the use of video-animation and verbal narration is likely to be superior to the current common practice of a clinician talking through the process of swallowing and providing a leaflet for more information. Print images and accompanying written explanation require visual processing of all content, in the same way that verbal information only is demanding on audio processing (Wilson & Wolf, 2009). In designing health information resources, it is important to consider that working memory has a limited capacity and patients are already under cognitive stress from their diagnosis (Wilson & Wolf, 2009). According to Mayer's multimedia learning theory (Mayer, 2003), information presented via different modalities has different

stores within working memory. Applying this to the current study, one might surmise that video-animation with narration not only offers a better medium for conveying a complex and sequential process, but also allows greater cognitive capacity for the individual to process this information by making use of both visual and audio stores.

The findings from this study together with the theoretical insights may offer some explanation for the mismatch between the information that speech and language therapists (SLTs) provide to patients pre-treatment and patients' understanding and recollection of the swallowing process (Brockbank et al., 2015; Govender et al., 2017). The timing at which such information has to be provided is unavoidably distressing for patients by virtue of them receiving a recent cancer diagnosis.

However, one may argue that an optimal presentation medium for both the context and the type of material to be communicated could reduce the cognitive burden for patients. Furthermore, as is noted in the literature, what patients report they understand is often an over-estimation of comprehension (Chapman, Abraham, Jenkins & Fallowfield, 2003). This assertion is based on extensive work investigating lay understanding of terms used during cancer consultations (Chapman et al, 2003). The scope for a SLT clinician to verify comprehension about dysphagia could be increased through the interactive format afforded by the use of video-animations.

Although only one patient voiced concerns about the image being "too medical" patients could be better prepared by providing more information about what to expect before showing the video. In practice, the authors anticipate that the use of such a video-animation will be one component of the SLT pre-treatment consultation. The animation could also serve as a helpful introduction for those

patients who may undergo an x-ray swallow assessment (modified barium swallow). Explaining the swallow mechanism using the animation may improve a patient's ability to understand his/her own modified barium swallow results. In this scenario, animation could be useful for therapy, particularly when discussing the rationale for swallowing exercise interventions.

The think-aloud task highlighted that patients needed to be allowed time and the opportunity to slow down the speed of the video and to watch repeatedly if required. Offering some of this control to the patient makes their learning more interactive, fostering a shared responsibility for the acquisition of knowledge. This may increase patient activation (Hibbard, 2016) in using this knowledge to inform decisions and formulate intentions to make positive health behaviour changes. The results of our preliminary study offer some support for this assertion, as several patients indicated that they would have been more inclined to participate in prophylactic swallowing exercise programs if they fully understood the process of swallowing and the ramifications of treatment on their own ability to eat and drink. Video-animation appeared to make this process more concrete and understandable. Our findings therefore seem to align well with the Common-Sense Model of Self Regulation (Leventhal et al., 2003; 2016).

We acknowledge the limitations of this study. The sample of patients selected had all received previous information about swallowing during their rehabilitation and so the responses from newly diagnosed patients may differ. However, as the primary purpose was to gather preliminary information, we were mindful to avoid recruiting newly diagnosed patients at this early stage. While we recognize that patient responses may therefore have been influenced by their previous experience, the

video-animation itself was new to patients and the think-aloud method partly counter-acted this limitation through allowing for ‘spontaneous and live’ responses. We also acknowledge that we cannot directly extrapolate these findings to newly diagnosed patients at this stage. Instead, this study was viewed as a necessary first step prior to including this method in the pre-treatment consultation of newly diagnosed patients. Based on the largely favourable results in patients from the same target population we can have greater confidence that video-animation *may* be similarly acceptable to newly diagnosed patients with head and neck cancer. The data suggests that this medium and content is appropriate, understandable and relevant to patients. Furthermore, despite being a small and preliminary study, useful insights have been obtained about a relatively unexplored aspect of managing patients with dysphagia. These insights may be useful for accumulating knowledge and understanding on this topic, and may be helpful to future research.

We believe that our chosen methodology is an important strength of this study. While the think-aloud method has been used extensively in the software and website development industry, its use in healthcare research is limited. However, as technology, the Internet and phone apps become a bigger part of patient care, think-aloud methods may become increasingly useful. The present study could serve as a helpful example for other healthcare researchers.

Conclusions and Implications

Video-animation appears to be a promising method of conveying complex information about the swallowing process. Using this medium could also serve as a focal point for discussing head and neck cancer treatment and the possible side

effects during pre-treatment consultations with a speech and language therapist. Video-animation lends itself well to a participatory interaction style in which patients may be more likely to spontaneously ask questions and become more engaged in acquiring knowledge about preserving good swallowing function. In practice, clinicians have the opportunity to tailor the narration ensuring greater personalization. The effectiveness of these strategies in increasing patients' understanding of swallowing and their intentions to make health behaviour changes such as undertaking prophylactic swallowing exercises is yet to be determined, and is the subject of our future research.

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Legend Captions:

Figure 1:

Diagram illustrating Leventhal’s Common-Sense Model of Self-Regulation of illness behaviour. Adapted from: Leventhal & Cameron (1987).

Figure 2 :

Still image of the video-animation app showing a normal swallow.

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