



A telehealth approach to conducting clinical swallowing evaluations in children with cerebral palsy



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ABSTRACT

Background: Accurate and timely evaluation of dysphagia in children with cerebral palsy (CP) is critical. For children with limited access to quality healthcare, telehealth is an option; however, its reliability needs to be investigated.

Aim: To test the reliability of an asynchronous telehealth model for evaluating dysphagia in children with CP using a standardized clinical assessment.

Methods and procedures: Nineteen children (age range 6.9–17.5) were assessed at three mealtimes via the Dysphagia Disorder Survey (DDS) by three clinicians (face-to-face evaluations). Mealtimes were video-recorded to allow asynchronous evaluations by a remote clinician who also completed approximately 1/3 of face-to-face evaluations. Agreement was tested on DDS variables and dysphagia severity.

Outcomes and results: Results revealed substantial to excellent agreement between face-to-face and remote assessments by the same rater (78–100%, $K_w = 0.64–1$) on all, but two variables (oral transport and oral pharyngeal swallow) and by different raters (69–89%, $K_w = 0.6–0.86$) on all but one variable (orienting). For dysphagia severity, intrarater agreement was excellent (100%, $K_w = 1$); interrater agreement was substantial (85%; $K_w = 0.76$). **Conclusions and implications:** Asynchronous clinical swallowing evaluations using standardized tools have acceptable levels of agreement with face-to-face evaluations, and can be an alternative for children with limited access to expert swallowing care.

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What this paper adds?

Children who live in rural areas or have mobility limitations may experience barriers in accessing quality healthcare services, including expert swallowing assessment and treatment. Telehealth has shown to be a promising solution to overcome these disparities. Over the last decade, there have been numerous studies examining the validity, reliability, and clinical utility of swallowing tele-evaluations in adult patients and these studies have reported positive results. However, the use of telehealth in evaluating swallowing function in children has not been investigated to date. Therefore, our aim was to exam-

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ine the reliability of a telehealth model for conducting asynchronous clinical swallowing evaluations using a standardized tool in children with cerebral palsy (CP).

Our study provides the first evidence that asynchronous clinical swallowing evaluations for children with CP using the Dysphagia Disorder Survey (DDS) are feasible and reliable. Specifically, using two measures of agreement (weighted kappa and % agreement) we showed substantial to excellent agreement between face-to-face and remote assessments by the same rater and different raters on most DDS items and dysphagia severity ratings. Factors such as using a standardized tool, pre-training to criterion, and obtaining high-quality video recordings appeared to have contributed to the high reliability seen in this study. Our study suggests that in situations where a dysphagia specialist is not easily accessible, clinicians may consider conducting asynchronous clinical swallowing evaluations for children with CP using the DDS. This study also adds to the existing evidence on the role of telehealth in enhancing access to healthcare for children with dysphagia.

1. Introduction

Swallowing disorders, otherwise known as oropharyngeal dysphagia, can be defined as difficulty with acceptance, manipulation, and safe transportation of foods and liquids from the mouth to the esophagus (Logemann, 1998). Dysphagia is prominent in children with cerebral palsy (CP) with its prevalence ranging from 36 to 90% (Dahl, Thommessen, Rasmussen, & Selberg, 1996; Fung et al., 2002; Reilly, Skuse, & Poblete, 1996; Stallings, Charney, Davies, & Cronk, 1993). When dysphagia is not effectively treated, it can have serious consequences, including failure in maturation of eating skills, failure to thrive, reduced quality of life, dehydration, respiratory compromise, and aspiration pneumonia, and may necessitate alternative means of nutrition (Fung et al., 2002; Rogers, Arvedson, Buck, Smart, & Msall, 1994; Stevenson, Haves, Cater, & Blackman, 2008).

Due to these potentially devastating consequences, accurate and timely evaluation of feeding and swallowing skills in children with CP is important. A comprehensive swallowing evaluation includes clinical and instrumental assessments. Clinical swallowing evaluations involve the clinician examining the patient for signs and symptoms of dysphagia at the bedside, making a subjective decision on the presence or absence of swallowing difficulties, and deciding whether an instrumental assessment is necessary (Arvedson & Lefton-Greif, 1998; Link, Willging, Cotton, Miller, & Rudolph, 2000; Rommel, 2006).

Instrumental assessments typically involve either the use of videofluoroscopy (Videofluoroscopic Swallowing Studies [VFSS]) or flexible endoscopy (Fiberoptic Endoscopic Evaluations of Swallowing [FEES]) (Rommel, 2006; Sheppard & Malandraki, 2015). VFSS is a real-time x-ray examination of the swallowing mechanism and exposes patients to small amounts of ionizing radiation. FEES does not involve radiation exposure, but requires the insertion of an endoscope to the oropharynx through the nasal cavity and can be difficult to perform in patients with movement disorders (Langmore, Kenneth, & Olsen, 1988; Langmore et al., 1998). Given these limitations, instrumental assessments are not the first choice in the evaluation of pediatric patients with CP; a clinical swallowing evaluation is typically the first, and sometimes the only necessary, step in the evaluation of these patients (Benfer et al., 2015; Sheppard & Malandraki, 2015). Although most clinicians use non-standardized methods to perform clinical swallowing assessments, there are a limited number of standardized clinical dysphagia assessments for children with developmental disabilities (Ortega, Ciamponi, Mendes, & Santos, 2009; Sheppard, Hochman, & Baer, 2014; Skuse, Stevenson, Reilly, & Mathisen, 1995; Sonies et al., 2009). Using standardized tools to perform or supplement the clinical swallowing evaluation process is preferable as they provide more reliable results and reduce clinicians' bias (Benfer, Weir, & Boyd, 2012; Sheppard et al., 2014).

For most children with CP who live in urban areas, access to dysphagia experts is feasible and convenient. Yet, for some children, for example those who live in rural areas or those who face moderate to severe gross motor limitations, just the opposite is true (Rowell, Pincus, White, & Smith, 2014). As a result, these children often experience poorer health outcomes (Rowell et al., 2014; Strasser, 2003). To address the needs of these patients, healthcare providers have started delivering healthcare related services using telecommunication technologies (i.e., telehealth). Telehealth services are typically offered in synchronous (e.g., interactions between the clinician and the patient in real-time) or asynchronous (e.g., interactions between the clinician and the patient via images, audio files, or recorded videos) modalities (Allely, 1995; McCue, Fairman, & Pramuka, 2010). Clinicians typically choose the modality that meets the needs of their patients and/or setting.

Research has identified many benefits to using telehealth, including increasing access to services (Jennett et al., 2003), decreasing wait and travel time (Shore, Brooks, Savin, Manson, & Libby, 2007; Wade, Karnon, Elshaug, & Hiller, 2010), reducing travel and healthcare costs (Shore et al., 2007; Wade et al., 2010), and reducing hospital re-admissions (Jerant, Azari, & Nesbitt, 2001). Regarding the management of dysphagia, telehealth has also been shown to significantly improve health outcomes and quality of care (Malandraki et al., 2013).

Specifically, over the last decade, there have been several research studies examining the effectiveness and clinical utility of telehealth services in dysphagia management (Malandraki, McCullough, He, McWeeny, & Perlman, 2011; Malandraki et al., 2013; Malandraki, Roth, & Sheppard, 2014; Sharma, Ward, Burns, Theodoros, & Russell, 2011; Ward, Burns, Theodoros, & Russell, 2013; Ward, Sharma, Burns, Theodoros, & Russell, 2012a, 2012b; Ward et al., 2007). Most of these studies have primarily focused on adult patients and have demonstrated positive results on the feasibility and reliability of remote dysphagia evaluations (Malandraki et al., 2011; Malandraki et al., 2013; Sharma et al., 2011; Sharma, Ward, Burns, Theodoros, & Russell, 2012; Ward et al., 2013; Ward, Sharma, Burns, Theodoros, & Russell, 2012a; Ward, E. C., Sharma, S., Burns, C., Theodoros, D., & Russell, 2012b; Ward et al., 2007). However, the use of telehealth in evaluating dysphagia in children has not been examined.

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