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Research Article

Family-Based Rehabilitation Oromotor Exercise for Pediatric Patients with Oral Phase Dysphagia

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Abstract

Introduction: Pediatric dysphagia can impact the nutritional sufficiency and feeding safety of pediatric patients. During the COVID-19 pandemic, pediatric patients with dysphagia had limited access to rehabilitation treatment due to lockdowns and resource shifts. Therefore, home-based therapies for dysphagia were expected to provide patients with a better opportunity to receive therapy more frequently without increasing their risk and costs.

Methods: We included pediatric patients with oral phase dysphagia without any involvement of the pharyngeal phase. Each patient participated in a 12-week family-based rehabilitation program that incorporated oral motor exercises, sensory stimulation, and functional chewing training. All subjects underwent a clinical examination and video-fluoroscopic swallowing study procedure before and after program. The parameters measured were clinical symptoms, body weight, Functional Oral Intake Scale (FOIS), Dysphagia Severity Scale (DSS), and Modified Barium Swallow Impairment Profile (MBSImP) score.

Results: Ten patients were included in the study, with 40% of them having cerebral palsy as their primary underlying diagnosis. After 12 weeks of treatment, participants experience no worsening of clinical symptoms. Notably, body weight, FOIS, DSS, and oral MBSImP scores all significantly improved ($p>0.001$, $p=0.001$, $p=0.003$, $p=0.027$, respectively), while the 8-point PAS did not change significantly ($p=0.170$). Among the MBSImP components, the treatment significantly enhanced lip closure ($p=0.005$) and tongue control ($p=0.045$).

Conclusion: Family-based oral motor exercises have shown a beneficial impact on both clinical and functional aspects of oral phase swallowing in pediatric. Further investigations with larger sample sizes should be done to provide more comprehensive insights for the protocol.

Keywords: Pediatric; Dysphagia; Oral phase; Home based; Rehabilitation

Abbreviations & Acronyms

VFSS: Video-Fluoroscopic Swallow Studies; COVID-19: Corona Virus Disease of 2019; PM&R: Physical Medicine and Rehabilitation; MBSImP: Modified Barium Swallow Impairment Profile; FOIS: Functional Oral Intake Scale; DSS: Dysphagia Severity Scale; PAS: Penetration Aspiration Scale; CP: Cerebral Palsy; SD: Standard Deviation

Introduction

Swallowing difficulties or dysphagia is found in approximately 500.000 children in the United States, commonly caused by factors like premature birth, developmental delays, neuromuscular disorders, anatomical irregularities, and cardiopulmonary diseases [1]. The clinical assessment of pediatric dysphagia involves medical history taking, physical examination, and objective diagnostic techniques like Video-Fluoroscopic Swallow Studies (VFSS). VFSS, also known as modified barium swallow study, offers a visual representation of the oral cavity, pharynx, larynx, and upper esophagus. It also provides insights into the functioning and coordination of all these areas during the dynamic swallowing process. This assessment allows for the visualization of the oral-preparatory, oral, pharyngeal, and esophageal stages of swallowing [1,2].

Pediatric dysphagia is closely linked to nutritional sufficiency and feeding safety, leading to significant morbidity and mortality if diagnosed late and left untreated [2,3]. Dysphagia can result in pulmonary aspiration, which may then result in a physical airway obstruction, leading to symptoms such as atelectasis or consolidation and an increased risk of infection, thus leading to pneumonia with a mortality rate of 0.785 [4,5]. To date, there is no single superior treatment for swallowing rehabilitation in children with dysphagia. An accurate feeding assessment serves as the foundation for evidence-based therapeutic interventions, and collaborative efforts among medical providers are essential to ensure the highest level of patient care [6].

Throughout 2020-2022, the corona virus disease (COVID-19) pandemic had a widespread impact across the world. In developing countries like Indonesia, the pandemic caused a significant shift in the delivery of medical care due to limited resources and technologies [7]. One of the medical services highly affected was rehabilitation care. Typically, pediatric rehabilitation care involves one-on-one

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outpatient services with therapists, patients, and their caregivers. However, during the COVID-19 pandemic, there were limitations on outpatient contact, along with a reduced number of medical care providers due to infections and the redirection of medical resources to other emergency departments.

On the other hand, pediatric patients with dysphagia require continuous therapy to improve their feeding skills and ensure they receive maximum nutritional intake safely. Home-based therapy provides patients with the opportunity to receive therapy more frequently without incurring additional risks and costs. Therapy administered by familiar figures such as caregivers is expected to enhance parent-child bonding and improve therapy adherence. Moreover, these home-based therapies can be carried out in a safer environment, reducing the risk of contracting the COVID-19 virus compared to prolonged outpatient treatments in a hospital setting [8-10]. We aim to evaluate the effectively of a family-based rehabilitation program for pediatric patients with dysphagia, ensuring the alignment of cost and risk reduction during the pandemic.

Methods

A total of ten patients from the pediatric rehabilitation outpatient clinic at CiptoMangunkusumo National General Hospital, Jakarta, Indonesia, were included in the analysis for this study. Participants were recruited using a convenience sampling method. Inclusion criteria for this study encompassed outpatient pediatric patients aged 0-15 years with exclusive oral phase dysphagia based on VFSS evaluations and having caregivers capable of adhering to research instructions. Exclusion criteria involved patients with active acute diseases, cancer, those unable to comply with research procedures and hospital visits, or those concurrently enrolled in other investigative studies. Dropout criteria were defined as patients who didn't adhere to treatment, meaning they undertook therapies for less than 75% of their prescribed regimen, failed to attend scheduled outpatient evaluations, or refrained from prescribed therapies for over one week. Originally, 12 patients were initially enrolled in the study; however, only 10 patients were included in the analysis. One patient couldn't complete the treatment due to a change in their living location, while the other had an acute infection necessitating inpatient care.

VFSS procedures were conducted by an experienced physiatrist and radiologist. The VFSS results were interpreted using the Modified Barium Swallow Impairment Profile (MBSImP) score [11]. Informed consent was obtained from the patients' caregivers. Patients who agreed to take part in this study underwent a three-month family-based rehabilitation treatment with the following procedures. During the initial meeting, caregivers received direct education from Physical Medicine and Rehabilitation (PM&R) doctors on how to perform one swallowing rehabilitation therapy. Caregivers were taught to conduct oral motor stimulation exercises, including cheek stretches, lip rolls, lip stretches, tongue exercises, gum massages, and sucking exercises. Additionally, they followed procedures recommended by VFSS, which included sensory stimulation involving variations in temperature, consistency, taste, and functional chewing training. Patients were provided with video tapes demonstrating the required therapies, an educational pamphlet, and a daily logbook to help track their progress. Patients were not restricted from taking their daily medications or visiting specialists in addition to their appointments with PM&R. Caregivers were enabled to reach out to the doctor team assigned to them whenever they required assistance. Video calls between the PM&R Doctor and caregivers were conducted once a week to evaluate their difficulties, the patient's clinical symptoms, the caregivers' understanding of the therapies performed, and adherence to the treatment plan. Patients and caregivers visited the outpatient clinic once a month to receive direct assessments from PM&R doctors. These assessments included an evaluation of clinical symptoms, weight measurement, Functional Oral Intake Scale (FOIS) evaluation [12], Dysphagia Severity Scale (DSS) assessment [13], and 8-point Penetration-Aspiration Scale (PAS) [14]. Definitions of the scoring instruments used are displayed in Table S1. Importantly, clinical scoring evaluations were carried out by a different independent doctor than those assigned to the patients. Towards the end of the third month, a second VFSS procedure was performed for evaluation purposes. The evaluated parameters were subjected to statistical analysis using Statistical Package for the Social Sciences software. The analysis involved the application of paired t-tests, which allowed for a comprehensive assessment of any significant changes and variations within the parameters before and after the family-based rehabilitation program.

Results

Ten patients were included in the study analysis with primary underlying diagnoses of Cerebral Palsy (CP) (40%), down syndrome (20%), laryngomalacia (20%), and other orofacial structure abnormalities (20%). The patients' age ranged from 6 months to 4 years, with an average age of 2.12 years at the time of their initial assessment. Complete participants' initial characteristics are presented in Table 1.

Table 2 illustrates the comparison of patients' body weight and dysphagia scores before and after the family-based rehabilitation program. After three months of treatment, none of the participants had worsening clinical symptoms. Within the measured parameters, body weight, FOIS, DSS, andoral MBSImP score displayed a significant improvement following the three months of home-treatment ($p>0.001$, $p=0.001$, $p=0.003$, $p=0.027$, respectively). The VFSS assessment was conducted using a thin liquid consistency. Consequently, the mastication and bolus preparatory stage in the MBSImP scoring was not applicable for our patients, as the evaluation specifically called for solid consistency and an assessment of the patient's chewing ability. Specifically, among the components of oral impairment from MBSImP, the family-based rehabilitation treatment significantly improved lip closure ($p=0.005$) and tongue control ($p=0.045$). The 8-point PAS did not yield a significant result, as indicated by a mean score difference of only 1.1 ($p=0.170$).

Discussion

The home rehabilitation program has yielded notable enhancements in various clinical parameters, which have a direct impact on the overall well-being of pediatric patients with dysphagia. The patients included were all below 5 years old in age (Table 1). This narrow age range minimizes the potential impact of developmental and anatomical changes on the study outcomes [3]. Notably, we observed substantial improvements in weight gain, as well as FOIS and DSS score. Furthermore, our findings reveal a noteworthy reduction in oral phase impairment, as evidenced by a significant decrease in the MBSImP score, especially in lip closure and tongue control components. These positive results underscore the potential of family-based rehabilitation programs to not only address the clinical needs of pediatric patients with dysphagia but also aid in cost-effectiveness and risk reduction in the context of a global health crisis like the COVID-19 pandemic.

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Table 1: Patient characteristics at initial assessment.

Patient characteristics	Result
Gender (male), n (%)	6 (60%)
Age at assessment (months), mean (SD)	25.40 (13.57)
Diagnosis, n (%)	
Cerebral palsy	4 (40%)
Down syndrome	2 (20%)
Laryngomalacia	2 (20%)
Orofacial structure abnormalities	2 (20%)
Weight (kg), mean (SD)	11.21 (4.53)
Height (cm), mean (SD)	83.5 (11.25)
Nutritional status (WHO), n (%)	
Under nutrition	3 (30%)
Normal	5 (50%)
Over nutrition	2 (20%)

SD: Standard Deviation; FOIS: Functional Oral Intake Scale; DSS: Dysphagia Severity Scale; MBSImP: Modified Barium Swallow Impairment Profile; PAS: Penetration Aspiration Scale.

FOIS is a seven-point rating system designed for clinical purposes to document changes in a patient's ability to consume liquids and food [12]. This scoring system demonstrated sufficient reliability and validity when applied to children, and it exhibited a notable association with both the severity of dysphagia and the risk of aspiration [12,15,16]. In this study, the average FOIS score showed a positive shift, increasing from 3.90 (SD=1.45) to 4.80 (SD=1.48) (Table 2). This improvement signifies that patients initially categorized as reliant on feeding tubes (FOIS 3) or limited to a single consistency oral diet (FOIS 4) have progressed by one scale to switch to oral diet or enabled for a more varied consistency in their oral diet (FOIS 5). This increase is very valuable, as it reflects a substantial enhancement in the patient's eating capabilities, which is pivotal, especially in the context of pediatric development milestones. Achieving even greater improvement in the FOIS score may require longer therapy duration or additional supplementary treatments, like neuromuscular electrical stimulation.

Similar upward trend is observed in DSS score. The average DSS score has shown improvement, rising from 4.80 (Standard Deviation (SD) = 1.03) to 5.60 (SD = 1.26) (Table 2). This indicates that patients previously categorized as experiencing occasional aspiration (DSS 4) or having oral issues (DSS 5) have progressed by one point to a stage where they no longer experience aspiration or face minimal problems (DSS 6) [13]. This one-point advancement holds significant importance, as it reduces the risk of aspiration in children. Minimizing the risk of aspiration is crucial, as it can subsequently reduce the likelihood of more severe complications and even mortality in these young patients. Aspiration is primarily associated with issues in the pharyngeal phase of swallowing, however it can also occur at different points in the swallowing process: before, during, or after swallowing [17]. Aspiration before swallowing is often linked to difficulties in retaining liquids in the oral cavity or a delayed onset of laryngeal closure after a bolus is propelled into the pharynx [17]. In contrast, aspiration during swallowing typically results from problems in airway protection; while aspiration after the swallow is usually caused by the accumulation of residue in the pharynx after swallowing [17].This research primarily focuses on enhancing the oral phase of dysphagia. As a result, the minimal improvements reported are likely to be most effective in addressing issues related to aspiration before swallowing, and may not necessarily address concerns during or after the act of swallowing.

MBSImP offers a standardized protocol for assessing the physiological impairments related to swallowing function [11], and in this study, we specifically focused on the oral components. The average MBSImP score demonstrated a reduction in oral impairment, decreasing from 7.10 (SD = 4.65) to 3.30 (SD = 3.34), resulting in an average difference of 3.80 (SD = 4.57), p = 0.027 (Table 2). This indicates that the home-based rehabilitation program has the potential to reduce impairments specifically in the oral phase of dysphagia.

Upon analyzing each component of impairment individually, it was observed that lip closure and tongue control exhibited significant improvements (p=0.005 and p=0.045, respectively) (Table 2). Previous research has shown that children with lip closure issues often have weaker lip-closing strength [18,19]. Consequently, exercises targeting the facial muscles responsible for lip closure were considered effective in enhancing lip-closing abilities. Both tongue control and bolus transports rely heavily on the coordination of the tongue [20]. In the case of tongue control during bolus holding, the tongue moves the food into the post-canine region and rotates laterally, positioning the food on the surface of the lower teeth for processing, if necessary. To prevent the bolus from falling backward into the oropharynx before processing and transportation are ready, it is situated between the tongue and the palatal seal [19,20]. The home treatment protocol includes stimulation and exercises for the anterior-medial part of the oral anatomy, including the cheek, lip, tongue, and gum. This likely contributed significantly to the improvement of lip and tongue muscle strength and function. However, it's important to note that some components require improvement in more posterior parts of the mouth, which cannot be adequately addressed through home exercise treatments.

A prior investigation involving 27 pediatric patients with CP demonstrated the positive impact of a novel oral motor exercise method on the swallowing process [22]. This included improvements in areas like lip closure and liquid control [22]. A systematic review addressing the effects of oral motor exercises in pediatric patients acknowledged that several studies reported favorable outcomes, particularly in addressing issues such as tongue thrusting [23]. However, due to variations in exercise methods, mixed study results, and the limited number of high-impact studies available, drawing an overall conclusion regarding the effectiveness of oral motor exercises remains challenging [22]. Nevertheless, there is promise in using oral motor exercises to enhance swallowing, particularly in the oral phase, involving functions related to the tongue, jaw, and lips.

In our study, we noticed a consistent increase in weight among all patients, and none of them experienced deterioration in their clinical dysphagia symptoms throughout the treatment. These findings strongly indicate that family-based rehabilitation exercises are both viable and safe for stable dysphagia patients. It's important to note, however, that we conducted careful participant screening, particularly focusing on caregivers who were well-educated and capable of following instructions. In clinical practice, we recommend that clinicians also assess the ability and suitability of caregivers to administer home therapies.

Based on other studies, factors influencing patient adherence to home-based programs include elements like social support and perceived barriers such as time constraints, work schedules, and daily routines [24]. In our study, the advantage of a small sample size allowed us to maintain frequent patient follow-ups and provide them with the necessary support to continue the home-based therapy. Consequently, the majority of patients successfully adhered to the

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Table 2: Comparison of dysphagia scoring before and after family-based rehabilitation program.

Parameter	Mean (SD) before program	Mean (SD) after program	Mean difference (SD)	Significance (p-value)
Weight (kg)	11.21 (4.53)	12.70 (4.23)	1.49 (0.60)	0.001
FOIS	3.90 (1.45)	4.80 (1.48)	0.90 (0.57)	0.001
DSS	4.80 (1.03)	5.60 (1.26)	0.80 (0.63)	0.003
Oral MBSImP score	7.10 (4.65)	3.30 (3.34)	3.80 (4.57)	0.027
Lip closure	2.20 (1.81)	0.10 (0.32)	2.10 (0.63)	0.005
Tongue control during bolus hold	1.00 (1.05)	0.30 (0.67)	0.70 (0.95)	0.045
Bolus transport/lingual motion	1.30 (1.42)	0.70 (1.25)	0.60 (1.65)	0.279
Oral residue	1.60 (0.84)	1.10 (0.99)	0.50 (1.18)	0.213
Initiation of pharyngeal swallow	1.00 (1.15)	1.10 (1.14)	0.10 (1.29)	0.811
PAS	2.50 (2.55)	1.40 (0.97)	1.10 (2.33)	0.17

SD: Standard Deviation; FOIS: Functional Oral Intake Scale; DSS: Dysphagia Severity Scale; MBSImP: Modified Barium Swallow Impairment Profile; PAS: Penetration Aspiration Scale

prescribed therapies for a three-month duration. However, it is worth noting that adjustments may be required when implementing home exercises in larger populations. This is in line with findings from larger studies, which have indicated that non-adherence in home-based rehabilitation programs can vary significantly, potentially reaching rates as high as 70% [24-26].

This study possesses notable strengths, being the first to investigate home-based therapy for dysphagia with a comprehensive assessment approach. This study utilizes a definitive confirmation of dysphagia through VFSS assessment, utilizing the MBSImP parameter and including additional scales like FOIS and DSS. This multifaceted evaluation provides a better understanding of the treatment's effectiveness. However, it's essential to acknowledge the study's limitations, which is the relatively small sample size. This constraint is largely due to the resource limitations commonly encountered in low- and middle-income countries like Indonesia. A larger sample size could offer a more robust analysis of the therapy's outcomes.

In Indonesia, the utilization of family-based rehabilitation remains relatively scarce, particularly within the context of pediatric patients. High-impact studies in this area are still lacking. However, there is a case report from Yogyakarta that highlights the feasibility of implementing family-based rehabilitation, which yielded positive outcomes, particularly in a high-risk infant [27]. In times like the pandemic, where access to healthcare is limited, family-based rehabilitation can serve as a valuable option for continuing a patient's therapy. However, this approach demands careful consideration from the attending physician, taking into account the patient's underlying medical condition and the readiness of the caregivers. Frequent and close follow-up is essential to prevent non-adherence and ensure correct exercise applications. The widespread adoption of home-based exercises in Indonesia still faces significant challenges due to the varying rural-urban distributions and disparities in education levels. However, it is not an unattainable goal. In the future, the integration of family-based rehabilitation into the national health insurance system could offer a promising solution. This would enable patients to receive scheduled home visits from healthcare professionals, improving accessibility and ensuring that more individuals can benefit from this form of treatment.

Conclusion

Family-based oral motor exercises have demonstrated positive effects on both the clinical and functional aspects of oral-phase swallowing in pediatric patients. However, there is a need for a study involving a larger population to provide a more comprehensive assessment of treatment efficacy.

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Supplementary Table

Table S1: Definition of dysphagia scoring instruments [11-14].

Dysphagia scoring instrument	Definition
Functional Oral Intake Scale (FOIS) [12]	1 – Nothing by mouth
	2 – Tube dependent with minimal attempts of food or liquid
	3 – Tube dependent with consistent attempts of food or liquid
	4 – Total oral diet of single consistency
	5 – Total oral diet of multiple consistency, but requiring special preparations or compensations
	6 – Total oral diet of multiple consistency without special preparations, but with specific food limitations
	7 – Total oral diet with no restrictions
Dysphagia Severity Scale (DSS) [13]	1 – Saliva aspiration
	2 – Food aspiration
	3 – Water aspiration
	4 – Occasional aspiration
	5 – Oral problems
	6 – Minimum problems
	7 – Within normal limit
Modified Barium Swallow Impairment Profile (MBSImP) [11]	Lip Closure
	0 – No labial escape
	1 – Interlabial escape; no progression to anterior lip
	2 – Escape from Interlabial space or lateral juncture; no extension beyond vermilion border
	3 – Escape progressing to mid-chin
	4 – Escape beyond mid-chin
	Tongue control during bolus hold
	0 – Cohesive bolus between tongue to palatal seal
	1 – Escape to lateral buccal cavity/floor of mouth (FOM)
	2 – Posterior escape of less than half bolus
	3 – Posterior escape of greater than half bolus
	Bolus transport/lingual motion
	0 – Brisk tongue motion
	1 – Delayed initiation of tongue motion
	2 – Slowed tongue motion
	3 – Repetitive/disorganized tongue motion
	4 – Minimal to no tongue motion
	Oral residue
	0 – Complete oral clearance
	1 – Trace residue lining oral structures
	2 – Residue collection on oral structures
	3 – Majority of bolus remaining
	4 – Minimal to no clearance
	Initiation of pharyngeal swallow
	0 – Bolus head at posterior angle of ramus (first hyoid excursion)
	1 – Bolus head in valleculae
	2 – Bolus head at posterior laryngeal surface of epiglottis
	3 – Bolus head in pyriformis
	4 – No visible initiation at any location
8-point Penetration-Aspiration Scale (PAS) [14]	1 – Material does not enter airway
	2 – Material enters the airway, remains above the vocal folds, and is ejected from the airway
	3 – Material enters the airway, remains above the vocal folds, and is not ejected from the airway
	4 – Material enters the airway, contacts the vocal folds, and is ejected from the airway
	5 – Material enters the airway, contacts the vocal folds, and is not ejected from the airway
	6 – Material enters the airway, passes below the vocal folds, and is ejected into the larynx or out of the airway
	7 – Material enters the airway, passes below the vocal folds, and is not ejected from the trachea despite effort
	8 – Material enters the airway, passes below the vocal folds, and no effort is made to eject

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