investigación •

ORAL-MOTOR THERAPY: STUDY OF A DISTANCE LEARNING EDUCATIONAL MODEL FOR PRIMARY CAREGIVERS

Terapia oromotora: estudio de un modelo educativo a distancia para cuidadores primarios

Terapia motora oral: estudo de um modelo de ensino à distância para cuidadores primários

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ABSTRACT

Eating and swallowing disorders are prevalent among children with neuromotor disabilities, significantly impacting their overall quality of life. The COVID-19 pandemic exacerbated the challenges by restricting access to health care, underscoring the necessity for innovative solutions with caregiver involvement. This study investigated the effectiveness of a distance learning educational model in oral-motor therapy for primary caregivers of children with neuromotor impairments in Mérida, Mexico. The quasi-experimental pretest-posttest design included thirty primary caregivers of children aged 2 to 12 with feeding and swallowing disorders from seven institutions. Twenty-three participants completed the program. The program encompassed theoretical sessions on various aspects of oral motor therapy and practical sessions focusing on handson training. Results revealed substantial enhancements in theoretical knowledge and practical competencies among caregivers, with competence levels exceeding 80% in all evaluated activities. Despite these positive outcomes, the study acknowledges limitations such as a small sample size and the absence of a control group. Addressing these constraints through future research endeavors will bolster the evidence supporting the effectiveness of this innovative caregiver-centric approach. Ultimately, integrating caregivers into the care team is imperative for improving the quality of life for children with neuromotor disabilities and effectively managing eating and swallowing disorders.

KEYWORDS: childhood feeding and eating disorders, Occupational Therapy, distance learning, caregivers

Resumen

Los trastornos alimentarios y de deglución afectan considerablemente la calidad de vida de niños y niñas con discapacidades neuromotoras. La pandemia de COVID-19 agravó estos desafíos al limitar el acceso a la atención en salud. Este estudio evaluó un modelo educativo de aprendizaje a distancia en terapia oral-motora, dirigido a personas cuidadoras de niños y niñas con discapacidades neuromotoras en Mérida, México. Participaron incialmente treinta personas cuidadoras de niños y niñas entre 2 y 12 años de edad con trastornos alimentarios y de deglución, quienes recibían atención en siete instituciones. 23 participantes completaron el programa. Se usó un diseño cuasiexperimental de prueba pre y post. El programa incluyó sesiones teóricas y prácticas. Los resultados mostraron mejoras significativas en el conocimiento teórico y en las competencias prácticas, con niveles de competencia superiores al 80%. Aun así, se reconocen limitaciones del estudio como el tamaño de la muestra y la ausencia de un grupo de control. Abordar estas limitaciones en investigaciones futuras fortalecerá la evidencia sobre la efectividad de este enfoque innovador centrado en la persona cuidadora, crucial para gestionar trastornos alimentarios y de deglución de manera efectiva y mejorar la calidad de vida de niños y niñas con discapacidades neuromotoras.

PALABRAS CLAVE: alimentación y trastornos alimentarios de la infancia, Terapia Ocupacional, enseñanza a distancia, cuidadores

Resumo

Os distúrbios da alimentação e da deglutição afetam significativamente a qualidade de vida das crianças com deficiências neuromotoras. A pandemia da COVID-19 exacerbou esses desafios, sendo que limitou o acesso ao atendimento. Este estudo avaliou um modelo educacional de ensino à distância sobre terapia oral-motora, orientado a cuidadores primários de crianças com deficiências neuromotoras em Mérida, México. Trinta cuidadores de crianças de 2 a 12 anos de idade com distúrbios de alimentação e deglutição de sete instituições participaram, sendo que 23 deles concluíram o programa. Um estudo quase experimental de pré-teste-pós-teste foi realizado. O programa incluiu sessões teóricas e práticas. Os resultados mostraram melhorias significativas no conhecimento teórico e nas competências práticas, com níveis de competência acima de 80%. Contudo, são reconhecidas algumas limitações do estudo, como o pequeno tamanho da amostra e a falta de um grupo de controle. A abordagem dessas limitações em pesquisas futuras fortalecerá as evidências respeito da eficácia dessa abordagem inovadora centrada no cuidador, crucial para melhorar a qualidade de vida das crianças com deficiências neuromotoras e gerenciar os distúrbios de alimentação e deglutição de forma eficaz.

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PALAVRAS-CHAVE: distúrbios alimentares e de alimentação na infância, Terapia Ocupacional, ensino à distância, cuidadores

INTRODUCTION

The COVID-19 pandemic has significantly impacted healthcare access and delivery, including oral-motor therapy for children with neurological disorders. Oral-motor therapy is crucial in Occupational Therapy services for this population, as it improves oral function, prevents complications like aspiration, malnutrition, and dehydration, improves feeding, and develops language and social skills, impacting their inclusion and quality of life (Barton et al., 2018; Garber, 2013; Voniati et al., 2021). Telerehabilitation has become a valuable alternative for patients with speech and swallowing problems, allowing for more frequent and continuous therapy sessions remotely (Nordio et al., 2018), translating into a more effective and efficient recovery (Agostini et al., 2015).

The frequency of oral-motor problems in children with neurological disorders can vary depending on the severity of the condition and other individual factors. In general, it is estimated that 50-75% of children with neurological disorders such as cerebral palsy, autism, and Down syndrome experience oral-motor problems (Hunt, 1982; Min et al., 2022), including difficulties with chewing, swallowing, and speech (Benson et al., 2013). However, oral-motor interventions have been insufficient in meeting the needs of children and their families.

Caregivers are crucial to the success of oral-motor therapy (Berker & Yalçın, 2008). They are vital in motivating and monitoring patients with oral-motor problems, providing an appropriate environment, and supporting therapy exercises (Davis & Pagliuco, 2022). During the pandemic, caregivers faced several challenges, including lack of access to therapy equipment and materials, mobility limitations due to travel restrictions and closure of in-person therapy centers, difficulties communicating with therapists due to physical distance and reliance on online technology, additional emotional burden, stress, and anxiety related to the pandemic (Beckers et al., 2021), and lack of supervision and face-to-face support from oral-motor therapists (Priyadharsini & Chiang, 2020).

Caregivers must acquire knowledge and skills skills related to oral-motor therapy to effectively support and assist children with motor and oral problems (Howe, 2018). This includes understanding typical mouth and swallowing functions, common oral-motor problems, basic skills to implement an effective treatment plan, exercise and therapy technique selection and progress monitoring, compensatory strategies, and dietary adaptations to improve swallowing and feeding (Maggioni & Araújo, 2020).

Studies about primary caregivers of children with oral-motor disorders have found that appropriate education and support are essential for caregivers to provide effective oral-motor therapy to their children (Rocha et al., 2015). Training in oral-motor therapy, understanding the specific needs of children, and the ability to implement appropriate techniques and exercises are key factors for successful therapy (Wiart et al., 2010). In addition, clear and regular communication with the occupational therapist and other healthcare professionals can help caregivers better understand the therapy process and maximize their outcomes (Phoenix et al., 2020).

Therefore, this study aims to investigate and assess the effectiveness of a distance learning educational model in oral-motor therapy for primary caregivers during the CO-VID-19 pandemic, bridging the gap in healthcare accessibility for every family in need.

Methods

Study design

The study followed a single-group quasi-experimental pre-test and post-test design focused on primary caregivers of children aged 2 to 12 years with feeding and swallowing disorders who were orally fed.

Participants

The study initially included 30 participants. The final sample consisted of 23 caregivers who completed the intervention. The participants were recruited through convenience sampling from seven non-profit civil associations and government institutions providing pediatric neuromotor therapy in Merida, Mexico. To be eligible, participants had to meet the following inclusion criteria: 1) be 18 years or older, 2) have access to an internet-enabled device, and 3) have signed the informed consent. The exclusion criteria were as follows: 1) not cohabiting with the child during their daily feeding, 2) the presence of health complications that would prevent them from performing manual, oral motor therapy techniques at home, and 3) the child under their care does not receive oral feeding.

Intervention: Oral-motor therapy training

The development of the program involved creating evaluation forms, practice mannequins, multimedia presentations with theoretical content, and prerecorded videos with practical exercises. Participants were divided into six groups based on their availability for online meetings, and practice mannequins were provided to them through the associations they attended or delivered to their homes.

A licensed occupational therapist conducted the oral-motor therapy training program using video conferencing platforms and prerecorded videos. The program consisted of eight theoretical sessions conducted in real-time via video conferencing, followed by eight practical sessions where the therapist showed and demonstrated exercise videos, and participants were asked to perform the exercises using their mannequins. Feedback was provided, and participants were encouraged to practice with the videos at their convenience. Each session lasted 30 minutes and occurred twice weekly for eight weeks, totaling 16 sessions. If a participant could not attend a session, it was rescheduled with another group. To complete the intervention, participants had to attend at least 80% of the sessions. The program aimed to enhance participants' knowledge and psychomotor skills related to oral-motor therapy, including information about cerebral palsy characteristics, swallowing phases, feeding abilities, and passive exercises that caregivers could perform at home.

Assessment

Initial interview and pretest. At baseline, the therapist responsible for the project conducted a direct structured interview to collect participants' socio-demographic profiles and clinical characteristics of the child under their care. The initial interview consisted of 10 questions and assessed the following dimensions: the caregiver's and child's demographic information, the child's diagnosis and previous rehabilitative treatment, gross motor function level, feeding method (oral, tube, or both), independence level and eating duration, use of adaptations during meals, difficulty with solid food or liquids, dental care received, and information received from professionals about child's feeding abilities.

Following the initial interview, all participants completed a pretest consisting of an online 10-item test to assess their knowledge of cerebral palsy characteristics, swallowing phases, dysphagia, and feeding abilities before attending the oral-motor therapy training course. The self-administered theoretical knowledge questionnaire was used. This instrument, created by the project lead, consists of 10 objective-response items designed to assess the content covered in the program. Each item is scored as "Correct" (1 point) or "Incorrect" (0 points). It was developed using Google Forms, with a final score of 0 to 10.

Subsequently, participants performed oral-motor therapy with the practice mannequin during a video call, and a checklist was used to evaluate their prior knowledge of passive oral-motor exercises. The questionnaires used were developed following the guidelines proposed by dos Santos and Fernández (2013).

Post-test. After completing the 8-week training course, participants' performance in oral-motor exercises was evaluated using the same checklist during an online video call. This assessment included grading the order and rhythm of each exercise, series repetition, position, and pressure applied with the hands. The checklist comprises several items designed to evaluate the execution of specific exercises. Each item is assessed based on a scale that includes three possible scores: 0 points for unsatisfactory performance, 1 point for performance needing improvement, and 2 points for satisfactory execution. The complete instrument is found in Appendix 1, and the scoring criteria are:

- Exercise sequence: This criterion assesses whether the exercises were conducted in the correct order. A score of 2 indicates that the exercises were performed in the appropriate sequence, 1 suggests room for improvement, and 0 means an unsatisfactory sequence.

- Series repetitions: This item focuses on the number of repetitions completed for each exercise. A score of 2 reflects the desired number of repetitions achieved, 1 implies room for improvement in the number of repetitions, and 0 suggests that the repetitions were inadequate.

- Hand pressure: Hand pressure evaluates the force applied during the exercises. A score of 2 suggests that the right amount of pressure was applied, 1 indicates the need for improvement in the application of pressure, and 0 means that the hand pressure was unsatisfactory.

- Exercise rhythm: This criterion assesses the rhythm or tempo of the exercises. A score of 2 means that the exercises were conducted at the appropriate rhythm, 1 indicates a need for improvement in maintaining rhythm, and 0 suggests that the rhythm was unsatisfactory.

- Hand position: Hand position evaluates the correctness of hand placement during the exercises. A score of 2 suggests that the hands were correctly positioned, 1 implies room for improvement in hand positioning, and 0 indicates unsatisfactory hand placement.

Additionally, participants completed the 10-item test with the same content as the pretest. Finally, participants provided feedback on their satisfaction with the tele-program by completing a survey.

The assessments were administered by the same therapist who conducted the initial evaluation. To prevent and control potential biases, the therapist was blinded to participants' pre and post-test scores until the study's completion, and two measures were implemented. An independent reviewer cross-checked a subset of assessments, ensuring inter-rater reliability. Any discrepancies were addressed through discussion and consensus, minimizing potential biases and ensuring the integrity of the evaluation process.

The instruments used in the study underwent a validation process, with a high concordance rate of 90% among four experts, indicating their suitability for assessing the intended dimensions.

Data Analysis

The authors performed the following statistical analyses to assess the theoretical questionnaire: The Shapiro-Wilk Test was used to determine the normality of scores before and after the program. In contrast, the Wilcoxon signed-rank test, a non-parametric test, was used to measure caregiver knowledge after the intervention.

The Shapiro-Wilk and Wilcoxon signed-rank tests were also used to evaluate the participants' practical competencies by comparing the post-test scores to confirm if the participants learned at least 80% of the practices.

Ethical procedures

The Ethics Committee of the School of Medicine at the Autonomous University of Yucatan approved the study (Folio No 04-21), ensuring it adhered to ethical and legal guidelines. The study involved voluntary participation, without coercion or pressure, to complete the caregiver training program. Participants were provided with comprehensive information about the study's objectives, procedures, and potential risks and benefits. They provided written informed consent before commencing their involvement.

Participants' anonymity was ensured by using unique identifiers in all documents and records, and personal data and contact information were kept confidential. Potential harm to participants was minimized through safe training sessions and support from a licensed physical therapist. Participants were transparently informed about the study outcomes and provided individualized feedback on their progress. Measures were taken to prevent conflicts of interest that could influence data collection, analysis, or interpretation. The study's ethical considerations were carefully considered to ensure the integrity and well-being of participants.

Results

The one group started with 30 participants, and the final sample included 23 caregivers who completed the intervention (21 females, 2 males; mean age 35 ± 20 years). The participants' characteristics are described in Table 1.

The average number of hours taken per participant was 7.5 hours. The number of absences per participant ranged from 0 to 3, with an average of one absence per person. The reasons for these absences correspond 64% to health reasons (illness of the participant, of the child in his/her care, or of a family member who required their assistance) and 29% due to technical failures to connect (interruption of the internet connection, malfunction of the electronic device, failure of the platform).

Characteristic	Category	Frequency	Percentage
Sex	Female	21	91%
	Male	2	9%
Rol	Mother	15	65%
	Aunt	4	18%
	Father	2	9%
	Grandmother	1	4%
	Sister	1	4%
Occupation	Housewife	11	48%
	Employee	8	34%
	Student	2	9%
	Retired	2	9%
Scholarity	Master	1	4%
	Graduate degree	12	53%
	Highschool	5	22%
	Secondary	4	17%
	Elementary	1	4%

Table 1.	Socio-demo	graphic c	haracteristics
		0	

Source: Author's o	wn elaboration.
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Of the children in their care, 12 are male and 11 are female. Their ages range from 2 to 12 years, with an average of 6 years. In this study, the medical diagnoses of the children were as follows: Spastic Cerebral Palsy, Athetotic Cerebral Palsy, Dyskinetic Cerebral Palsy, Down Syndrome, Autism Spectrum Disorder, and Pallister-Killian Syndrome.

Spastic Cerebral Palsy was diagnosed in 48% of the total sample, while Athetotic Cerebral Palsy and Dyskinetic Cerebral Palsy were present in 9% each. Down Syndrome accounted for 17% of the sample, Autism Spectrum Disorder represented 12%, and Pallister-Killian Syndrome was found in 5% of the children.

A sum of all correct scores of theoretical knowledge that primary caregivers had before and after the intervention was computed. A new variable was generated to analyze the treatment effect on knowledge, representing the difference between the total post-intervention knowledge and the total pre-intervention knowledge. The means of pre-intervention knowledge were (1.30, SD = 1.18), and those of post-intervention knowledge were (8.48, SD = 1.4).

To compare the total scores of correct answers in theoretical knowledge among caregivers before and after the program, it was found that there is no normality in the total scores (SW = .89, p = .016). Therefore, the Wilcoxon signed-rank test was conducted to analyze the change in knowledge generated by the intervention. It was observed that the knowledge of primary caregivers increased (z = 4.22, p < .001) due to the intervention. The median total knowledge of caregivers at the pre-test was 1 correct answer, and at the end of the intervention, the median total knowledge was 9 correct answers (see Figure 1).



Figure 1. Comparison of total theoretical knowledge pre and post test

Source: Author's own elaboration.

On the other hand, in evaluating the practice to make the comparison of a sample with an expected value, the normal distribution analysis of the post-test scores of the treatment was performed first. The results are shown in Table 2, and it can be observed that the scores do not follow a normal distribution; therefore, it is convenient to use nonparametric tests that make use of the median of the data for the comparison of a sample with an expected value.

Variable	Shapiro-Wilk W	Degree of freedom	Significance p-value
Order	0.629	22	< 0.001
Repetition	0.665	22	< 0.001
Pressure	0.655	22	< 0.001
Rhythm	0.544	22	< 0.001
Position	0.803	22	< 0.001

 Table 2. Normality tests for the study variables

Source: Author's own elaboration.

To perform the Wilcoxon signed-rank test on a sample, the scale scores had to be converted to a value between 0 and 100 points. For this, each person's scale score was divided by the potential scale values. In this manner, the score is expressed as a percentage of the overall scale. In this case, a post-test score of more than 80% indicates that the individual has considerably mastered the therapy.

As shown in Figure 2, the scores obtained by the participants are significantly higher than the expected score of 80% under a significance level of p < 0.001. This can mean that people have learned at least 80% of the practice performed in the post-test in all the activities and tasks performed.



Figure 2. Wilcoxon signed-rank test for one sample

Note: The Wilcoxon signed-rank test was significant at the 0.001 level.

Source: Author's own elaboration.

Discussion

First and foremost, our study's completion rate of approximately 77% is a noteworthy finding. It indicates that caregivers were willing and able to engage in a telehealth-based training program, even in cases where they may have limited prior experience with technology or faced logistical challenges. This aligns with previous research by Mitchell et al. (2016), which found that caregivers of children with chronic conditions demonstrated a high level of satisfaction and engagement with telehealth interventions. This collective evidence suggests that telehealth can be a feasible and acceptable mode of delivering caregiver training programs, emphasizing its potential to bridge geographical gaps in healthcare access.

Our study highlighted specific areas of oral-motor therapy where caregivers showed a significant improvement in knowledge and skills. Notably, their understanding of cerebral palsy characteristics, feeding abilities, and the consequences of feeding and swallowing disorders improved substantially. This is consistent with the findings of Moreno-Chaparro et al. (2022), whose review reported similar improvements in caregiver knowledge and competence after telehealth-based interventions. However, our study also identified areas related to feeding function and adaptations where caregivers showed less significant improvements. This echoes the findings of Kelso et al. (2009), who noted that certain aspects of caregiver training may require more focused and intensive support. These nuanced results emphasize the need for tailored training approaches that address caregivers' specific challenges in oral-motor therapy. Similarly, the study conducted by Kelso et al. (2009) examined speech therapy training through tele practice and found significant improvements in participants' skills to provide speech therapy to their children. This finding is consistent with the results of our study, which also demonstrates significant improvements in caregivers' understanding of oral-motor therapy after completing the training program.

Furthermore, Traube et al. (2020) explored telemedicine teaching approaches for parents and discovered that parents who participated in the program successfully gained the essential skills to work with their children. This supports the idea that telemedicine might be helpful for training caregivers and enhancing their skills. However, it is crucial to emphasize that, similar to our research, specific components may be more difficult to learn via telemedicine. For instance, the adaptation of feeding functions and adaptations in oral-motor therapy showed fewer significant improvements in our study, suggesting that these aspects may require more specific training approaches or additional resources.

Additionally, we utilized nonparametric tests to compare post-test scores with an expected value. The results demonstrated that participants' scores significantly exceeded the expected score of 80%, suggesting they had gained substantial knowledge and skills related to oral-motor therapy. These findings underscore the positive impact of the telehealth-based training program on caregivers' ability to provide effective oral-motor therapy to children with feeding and swallowing disorders.

The diverse medical diagnoses represented in our study population mirror the complex and variable conditions that caregivers often face. This diversity underscores the importance of individualized approaches to therapy and support. Our study demonstrated that telehealth can be a valuable tool in delivering tailored training, overcoming geographical barriers, and expanding access to specialized care. Similar findings were reported by Trauble et al. (2020), who highlighted the role of telehealth in providing individualized support for caregivers of children with developmental disorders. Collectively, these studies emphasize telehealth's potential to enhance the quality and accessibility of care for children with complex needs.

Limitations

Despite these promising results, we acknowledge several limitations in our study. The absence of a control group limits our ability to establish causality definitively. Future research should consider incorporating control groups to strengthen the evidence base for telehealth interventions. Additionally, the reliance on self-report measures, such as questionnaires and checklists, may introduce potential biases and measurement errors. Objective measures of caregiver performance and child outcomes could provide a more comprehensive assessment of the program's effectiveness.

CONCLUSION

This study contributes to the growing body of literature supporting the efficacy and acceptability of telehealth-based caregiver training programs, particularly in the context of oral-motor therapy for children with feeding and swallowing disorders. While our findings are promising, further research is needed to address limitations, including the absence of a control group and reliance on self-report measures. Nevertheless, the results underscore the potential of telehealth to improve caregiver knowledge and skills, enhance individualized care, and bridge geographical gaps in healthcare access, ultimately benefiting children with complex needs and their caregivers.

Authors' contribution:

The first author designed and carried out the intervention program, personally implemented and supervised all phases of the program, collected and analyzed the data resulting from the intervention, and actively participated in the drafting and revision of the manuscript. The second author supervised the research from conception to completion, participated in the initial planning and design of the study, coordinated communication between the different work teams, led the writing of the manuscript, and was responsible for correspondence with the journal. The third author actively participated in the review of the related literature, assisted in preparing the manuscript, and provided comments and suggestions.

Conflict of interest statement:

The authors of this article declare that they have no financial or personal conflicts of interest that could influence the objectivity or impartiality of the presented content. Furthermore, the authors affirm that they have not received any funding or support from any organization that may have a direct or indirect interest in the research or the results presented in this article.

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Appendix I

Evaluation for exercise #				
	Unsatisfactory	Below expectations	Satisfactory	
Item (For exercises 1-5)				
	(0 points)	(1 point)	(2 points)	
Performance of the exercise in the				
corresponding order				
Series' repetitions				
Hand pressure				
Pace of the exercises				
Position of the hands				
Total per exercise				
7-61-6-64				
l otal global				
Note: 10 points maximum per exercise	. 50 points maximu	ım as global score. T	he total is	
multiplied for 2 (percentage basis).				
Exercises:				
Exercise #1: Jaw stabilization				
Exercise #2: Masseters massage				
Exercise #3: Mouth closure stimulation				
Eversise #4: Lin passive range of motion				
Exercise #4: Lip passive range or motion				
Exercise #5: Oral structure mobilization				

Source: Author's own elaboration.