Program development and initial implementation report

Development and Initial Implementation of an Online Program for Caregivers of Children with Feeding and Swallowing Disorders: A Five-Stage Model

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ABSTRACT

Aim: Feeding and swallowing disorders in children with neurological disabilities affect their nutritional and respiratory status as well as their quality of life, which requires timely and ongoing care. However, in-person professional care requires time and resources for both the healthcare institution and the infants' caregivers. The purpose of this manuscript is to describe the development of an online program designed to train caregivers in addressing the feeding and swallowing issues of children with cerebral palsy at home, as well as to discuss possible contributions and limitations.

Method: Following a five-stage model, a needs analysis was conducted (phase 1) to identify the primary challenges faced by caregivers. Based on this analysis, a 16-session intervention was developed (phases 2–3), which included video modules, practical materials, and audiovisual content intended for online conferences.

Results: An initial implementation of the program was carried out, and participant feedback informed the refinement of the intervention (phases 4–5). Adjustments were made to the number of sessions, the scheduling of the program, and the digital platforms used, in order to improve accessibility and caregiver engagement.

Conclusion: The content of the program was successfully designed for online implementation. However, further research is needed to assess its feasibility, effectiveness, and long-term impact on caregivers and the children in their care.

Keywords: Cerebral Palsy, Feeding and Swallowing Disorders, Oral-Motor Therapy, Caregiver Training, Telehealth.

INTRODUCTION

Neurological disabilities in children may severely impact basic functions such as feeding and swallowing (van den Engel-Hoek et al., 2015). These oral-motor dysfunctions increase the risk for choking, aspiration, and malnutrition, which constitute life-threatening events (Sjögreen et al., 2018). In children with cerebral palsy, impaired oral-motor function has been consistently associated with malnutrition, recurrent respiratory

complications, including aspiration pneumonia, and reduced quality of life for both children and their caregivers. These consequences highlight the importance of early identification and effective feeding management strategies that can be sustained in the home environment. Feeding and swallowing disorders (FSD) in children include *feeding disorders* such as difficulties in sucking, eating from a spoon, chewing, or drinking from a cup; and *swallowing disorders* (i.e., dysphagia), defined as difficulties with moving food or liquid from the mouth, throat, or oesophagus to the stomach (The American Speech-Language-Hearing Association, 2019).

Cerebral palsy (CP) is the most common motor disability in childhood (Oskoui et al., 2013). CP describes a group of disorders that affect a person's ability to move and maintain balance and posture, and feeding and swallowing disorders are among the most common clinical manifestations of CP, with a prevalence of up to 90% (Centers for Disease Control and Prevention CDC, 2021; Lefton-Greif & Arvedson, 2007).

Health professionals, such as physical and occupational therapists, working with children who have FSD frequently incorporate oral-motor exercises into their treatment plans, including active exercises (e.g., active range of motion, stretching), sensory applications (e.g., heat, cold, electrical stimulation), and passive exercise (Clark, 2003; Logemann, 2000). Examples of passive exercises include massage, stimulation, tapping, vibration, and exercises in which the movement is provided by the therapist or caregiver. These procedures are applied to provide sensory input, improve circulation, and preserve or enhance joint flexibility (Ottenbacher et al., 1981). The exercises included in the present program belong to this category. The content of the present program was developed by integrating evidence from the literature on oral-motor therapy, feeding adaptations, caregiver education, and telehealth-based rehabilitation. This multicomponent approach was selected to address both the technical skills required to support feeding and swallowing and the educational needs of caregivers providing daily home-based care.

The main benefit of the oral-motor exercises is to normalise feeding patterns by reducing abnormal oral reflexes, facilitating normal muscle tone, or desensitising the oral region. Additionally, the caregiver could facilitate an efficient feeding practice, including the use of appropriate utensils and providing appropriate postural and physical support for positioning and self-feeding (Adams et al., 2012). It is important that the recommended interventions are discussed with the caregiver in order to choose the best suited for the individual patient, taking into consideration their feeding skills, needs, and the support the caregiver can provide (Sjögreen et al., 2018).

A multidisciplinary therapeutic presence is more accessible with telehealth. This approach should be patient-centric, considering the ability of the family to participate and take on more daily responsibilities in the child's natural environment. Numerous studies involving children with Autism Spectrum Disorder have supported parent training via telehealth as an evidence-based practice, acceptable to parents and reliably delivered by therapists (Bearss et al., 2018; Ferguson et al., 2019).

Some conditions (e.g., mobility difficulties, vulnerability to outdoor hazards, time availability, and pandemic alerts) impose strict restrictions on in-person therapies. Children with CP, their caregivers, and therapists then find themselves in need of becoming more involved in the children's treatment. By learning basic skills, therapy could be continued at home; as users become more familiar with the use of online programs, this tendency is expected to increase (Ben-Pazi et al., 2020).

Caring for children with CP at home is challenging, but online accessibility presents caregivers with the opportunity to continue giving the best care possible. Accessible, continuous care even during social distancing may help reduce the risk of secondary complications, thanks to the utilisation of online platforms that may help minimize deterioration and irreversible physical, emotional, and behavioural damage as well as provide

reassurance to families. Telehealth allows providers to perform healthcare from a distance using online platforms. With interactive video connection, transmitting information in both directions simultaneously (telehealth) combined with pre-recorded educational resources, the continuity of treatment could be conducted as part of the home health care.

Objective of the Study

The growing evidence supporting oral-motor therapy highlights the importance of ensuring continued access to these interventions. However, circumstances such as social distancing may limit the delivery of conventional face-to-face services, creating the need for alternative approaches to caregiver training through telehealth. Therefore, the use of telehealth with online training programs for parents and informal caregivers is proposed as a promising approach that warrants systematic development and evaluation. This manuscript aims to describe the development and preliminary implementation of an online training program for caregivers of children with feeding and swallowing disorders in Yucatan, Mexico, following a five-stage model for online healthcare training. The program was developed using a systematic staged methodological framework that integrated needs assessment, planning, content development, preliminary implementation, and evaluation to ensure a transparent and reproducible development process.

METHODS

The development process and preliminary implementation of the Oral-Motor Therapy Online Program (OMOP) are presented sequentially following the guidelines and stages proposed by Dos Santos and Fernandez (2013) for designing and evaluating online health training educational models: Needs analysis, Planning, Development, Implementation, and Evaluation (Figure 1).

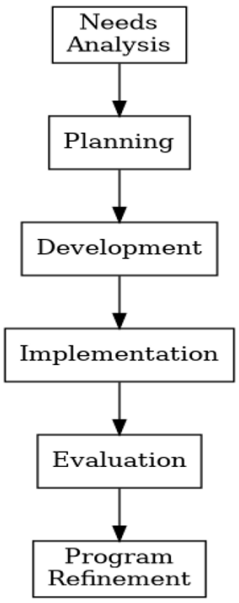

Figure 1. Five-stage methodological framework used for the development and preliminary implementation of the Oral-Motor Therapy Online Program (OMOP)

This five-stage framework was selected because it provides a structured approach to the design, implementation, and preliminary evaluation of telehealth educational programs, facilitating a systematic development process and future replication of the intervention. The implementation stage was conducted in a small sample of caregivers of children with CP to obtain feedback on the OMOP.

Ethical Considerations

Only the preliminary implementation (stage 4) and evaluation (stage 5) of the oral-motor therapy online program (OMOP) involved human participants. The preceding stages (needs analysis, planning, and development) focused exclusively on the design of the educational intervention, the development of training materials, and consultation with rehabilitation professionals, without the collection of research data from participants.

The preliminary implementation, including participant recruitment, data collection, and program evaluation, was conducted as part of a research protocol approved by the Research Ethics Committee of the Faculty of Medicine, Autonomous University of Yucatan (approval no. 04-21). All participants provided written informed consent prior to enrollment. Participation was voluntary, all procedures were conducted in accordance with the ethical standards of the approving institutional research ethics committee and the principles of the Declaration of Helsinki, and the confidentiality of participants' information was maintained throughout the study.

Stage 1- Needs analysis

Information was collected about the needs and strategies to improve feeding skills in children with CP and FSD. A meeting was conducted with a physical and two occupational therapists working at a neuromotor therapy centre called Solyluna, located in Merida (Mexico), in order to determine the ideal method to facilitate the oral-motor therapy at home performed by caregivers and to plan a schedule according to the identified topics that would be suitable considering the characteristics and context of the population attending this centre. This phase resulted in four essential needs for the program: 1) The children must continue their treatment aligned with their routine at home, especially during feeding time; 2) the caregiver must understand the basics of the mouth and face biomechanics during feeding and swallowing in order to identify potential risks, to recognise the benefits of providing adequate care and to prevent complications; 3) occupational adaptations and simple passive exercises are key to home health care; 4) the instructor must ensure that participants fully master the performance of the exercises prior to implementing them with their children.

Stage 2- Planning

The OMOP was designed for a 12-session intervention consisting of 30-minute sessions, each including synchronous (i.e., online conferences) and asynchronous (i.e., video modules) methods. The relevant topics identified were motor and sensorial characteristics of CP, feeding and swallowing skills and their consequent disorders, and posture and functional adaptations during feeding and exercises of oral-motor therapy (Gisel et al., 2003; Rosenbaum, 2003; Trier & Thomas, 1998). The educational content of the OMOP was developed by integrating evidence from the literature on pediatric feeding and swallowing disorders, caregiver training, safe feeding practices, and telehealth-based rehabilitation. The practical component focused on passive extraoral exercises that could be safely taught to caregivers and reinforced through supervised practice. The Jiménez-Treviño (2014) method of neurological oral assessment was used as the reference to standardize these passive extraoral exercises; however, the overall design of the OMOP was informed by multiple sources of evidence, including clinical guidelines and research on pediatric feeding and swallowing disorders, caregiver education, and telehealth interventions. The content of the program with the final 16-session structure is presented in Table 1.

Table 1. Structure, content, and learning objectives of the Oral-Motor Therapy Online Program (OMOP)

Session	Theme / Practical activity	Learning objective / Expected competency	Sub-theme /Description
1 (TS)	Cerebral palsy characteristics	Recognize the motor and sensory characteristics of CP related to feeding.	a. CP definition b. Motor characteristics c. Sensory characteristics
2–3 (TS)	Feeding and swallowing skills	Identify the normal feeding and swallowing process.	a. Feeding and swallowing phases b. Motor-control c. Oral sensory input
4 (TS)	Feeding and swallowing disorders	Recognize common feeding difficulties and dysphagia.	a. Feeding difficulties b. Dysphagia c. Drooling
5–7 (TS)	Posture and functional adaptations	Apply positioning and adaptive feeding strategies.	a. Feeding posture and alignment b. Posture support c. Eating with a spoon d. Drinking from a cup e. Food texture
8 (TS)	Oral-motor therapy	Understand the rationale of passive oral-motor exercises.	a. Oral-motor therapy effects
9 (PS)	Introduction and choking first aid	Recognize safety procedures and treatment sequence.	Presentation of an explanatory video on first aid for choking in children. Presentation of the introductory video of the oral-motor exercises.
10–14 (PS)	*Five oral-motor exercises	Correctly perform each oral-motor exercise.	Five exercises are individually presented in video by session. Participants will practice each exercise during the session. It will be recommended to practice at home and use the videos again if necessary for each exercise.
15 (PS)	Integrated practice	Integrate all exercises into a complete routine.	Space for questions and feedback.
16 (PS)	Final practice and feedback	Demonstrate correct performance and receive feedback.	Participants will practice the 5 exercises together in the established order.

Notes. TS = Theoretical Session; PS = Practical Session; CP = Cerebral Palsy; OMOP = Oral-Motor Therapy Online Program.

** Oral-motor exercises: Jaw stabilization, Masseters massage, Mouth closure stimulation, Lip passive range of motion, Oral structure mobilization*

The specific aims of the OMOP regarding caregivers' skills were: 1) to be able to identify the motor-sensory characteristics of CP and the impact they have on the oral-motor development of their children, 2) to be able to perform the oral-motor therapy skills,

and 3) to be able to identify the correct posture and posture-support techniques to improve feeding and swallowing skills.

Stage 3- Development

The content development included the audiovisual presentations for each session, evaluation forms, practice mannequins for the participants and oral-motor videos for each exercise. The training materials were developed by the same physical therapist who served as the program instructor.

The videos of practical content were part of the asynchronous method, designed to be sent to each caregiver for home practice. Performance feedback was provided during the following session. The seven videos consisted of an introduction; five including exercise/practice, and a conclusion video, all lasting between 60 and 90 seconds. A link to these videos in their original language (Spanish) is attached as supplemental material.

The practice mannequins were intended to be used during the training and as a part of the evaluation assessment. They met the following characteristics: 1) a head measuring 20 cm in length and 54 cm in diameter, 2) nose, ears, lips, jaw and neck well-defined, and 3) made with expanded polystyrene (i.e., Styrofoam) and painted with acrylic paint.

The evaluation forms were designed according to the themes of the program and they aimed to rate the knowledge acquired of the theoretical and practical content. The forms consisted of a self-administered online test, a checklist for the exercises performed, which were evaluated through video conference with the instructor, and a self-administered online satisfaction survey.

To facilitate reproducibility, the structure of the program, session content, training materials, and video-based exercises were standardized before implementation, ensuring that all participants received the same educational content and practical instructions.

Stage 4- Potential Participants' Implementation

In order to test the interest in the topics selected and comprehension of the terminology used in both the program and the evaluation instruments, researchers approached potential participants from the hosting paediatric rehabilitation centre. Inclusion criteria consisted of: 1) being a caregiver of 18 years or older, 2) being the primary caregiver of a child with CP and FSD who is 2–12 years of age, and 3) having access to the Internet. Eligibility was based on the clinical diagnosis of cerebral palsy with feeding and swallowing disorders, as determined by the multidisciplinary rehabilitation team providing routine clinical care. Standardized assessments of baseline oral-motor function were not performed because the purpose of this preliminary implementation was to obtain feedback on the content, delivery, and refinement of the caregiver training program rather than to evaluate clinical outcomes in children. Exclusion criteria were: 1) having insufficient knowledge of the Internet and digital devices, 2) attending the therapy centre for less than one year, and 3) the child not being exclusively fed orally. There were no restrictions in terms of type of CP and caregiver relationship to the child. Only one caregiver per child was admitted as a participant. Seven participants agreed to join the research program and gave written consent. The socio-demographic and clinical characteristics of the caregivers and children included in the preliminary implementation are presented in Table 2. All procedures were conducted in accordance with the ethical standards of the approving institutional Research Ethics Committee and the principles of the Declaration of Helsinki. This initial implementation was intended to obtain preliminary feedback on the program before future feasibility and effectiveness studies. Therefore, a small convenience sample was considered appropriate to obtain preliminary feedback on the content, delivery format, terminology, and opportunities for program refinement before future large-scale evaluation. Participants completed an initial sociodemographic questionnaire and a baseline evaluation.

Table 2. Characteristics of caregivers and children participating in the preliminary implementation phase (n = 7)

ID	Caregiver				Child		
	Sex	Age	Relationship	Occupation	Sex	Age	CP subtype
01	Female	21	Aunt	Student	Female	2	Spastic
02	Female	34	Mother	Housewife	Female	8	Dyskinetic
03	Female	36	Mother	Housewife	Female	8	Spastic
04	Female	37	Mother	Housewife	Female	7	Dyskinetic
05	Female	33	Mother	Housewife	Male	5	Spastic
06	Female	40	Mother	Housewife	Male	9	Spastic
07	Female	40	Mother	Teacher	Male	9	Spastic

The testing implementation lasted two months, when home confinement was mandatory in Mexico and children were receiving real-time sessions online with their therapists. However, the time frame was close to the holiday period. Of the seven caregivers enrolled, five (71.4%) reported issues with attending the synchronous sessions, mainly due to time constraints (n = 3), persistent technical problems with the internet connection (n = 1) or family health issues (n = 1). Individual attendance across the 16 sessions was not systematically recorded; therefore, session-by-session attendance could not be analyzed.

Stage 5- Evaluation of the Program

The theoretical evaluation comprised 10 items: 8 multiple-choice and 2 open questions, designed in digital software (Google Forms) for online answering. The items that the program content evaluated included the definition of CP, feeding and swallowing skills, feeding and swallowing difficulties, posture alignment, adapted cutlery, and oral motor exercises. The practical evaluation comprised of a checklist evaluating the order, the series repetition, and the rhythm of each exercise as well as the position and pressure applied with the hands. Each aspect was rated from 0 to 4 (0= unsatisfactory, 2=Needs improvement, 4=Satisfactory). This rating is used for the 25 items that conform to the instrument and allows for a final maximum score of 100 points.

In addition, a satisfaction survey was developed to inquire about the participant's opinion of the program and the evaluation formats. It consisted of 10 multiple-option questions that ask about the content, duration of the sessions, comprehension of the terminology used, the lecturer's performance, the suitability of the oral motor exercise training via the online platforms, and the perception of the information learned. The survey also contained open-ended questions for the overall opinion of the program and suggestions to improve it. The satisfaction survey was designed to identify areas for program refinement rather than to provide quantitative outcome measures. Therefore, the results are presented descriptively to inform subsequent modifications of the intervention.

RESULTS

Due to the exploratory nature of this preliminary implementation and the small convenience sample, no inferential statistical analyses were performed. The evaluation was intended to identify implementation issues, participants' perceptions, and opportunities for program refinement rather than to assess effectiveness. The satisfaction survey indicated that: 1) the content of the program was complete and well explained, 2) the duration of each session was ideal, 3) the number of practical sessions was insufficient, 4) the cloud platform to access the practical videos was difficult to use, and 5) they would recommend the program to other caregivers.

Participants also suggested increasing the number of practical sessions. This feedback was interpreted as a recommendation for improving the design of the program rather than as an indicator of participant attendance, since the relationship between attendance and satisfaction was not evaluated.

Based on the feedback obtained, the basis for the further adaptation of the OMOP was established: The number of practical sessions changed from 4 to 8. The synchronous sessions should be in accordance with the school calendar; this way, the number of dropouts is expected to be reduced, as the sessions would be aligned with the caregivers' previous routine. To facilitate access to asynchronous sessions, the videos should be shared via the caregiver's mobile phones, in addition to a cloud computing folder. Furthermore, it was suggested that an online follow-up via mobile phone (e.g., WhatsApp application) could be useful to ease the communication between lecturer-caregiver and between multiple caregivers, as well as to provide reminders before each session. In order to increase the participants' attendance, different schedules that adjust to the caregivers' availability could be created (morning, afternoon and night groups). The content of the OMOP was also of interest to other caregivers, who take care of children with different neurological disabilities that present FSD (e.g., Down syndrome, neurodevelopmental disorders).

DISCUSSION

The present study describes the development of an online training program for caregivers of children with feeding and swallowing disorders in Yucatan, Mexico, following a five-stage model for online healthcare training. The OMOP is a telehealth intervention for caregivers of children with CP to improve caregivers' skills in managing FSD as their home health care. The Telehealth Development in Latin America framework (dos Santos & Fernandez, 2013) guided the development process, enabling the integration of existing research, theoretical frameworks, expert knowledge and participants' feedback. The selection of the educational content and practical activities was intended to maximize both usability and safety for home implementation while maintaining alignment with current evidence on caregiver-mediated interventions for children with feeding and swallowing disorders.

As previously described, the causes of paediatric dysphagia are on a continuum between psychosocial and organic factors, and in most cases, these symptoms can improve significantly with medical treatment, oral motor training, and behavioural therapy. Manikam and Perman (2000) suggested that feeding problems are rarely limited to the children but involve the whole family.

The benefits of oral motor treatment in any of these presentations (active exercises, oral sensorimotor, passive exercises) include improving a child's health by reducing the risk of aspiration during feeding and improving or maintaining nutritional status. But oral motor treatment also increases a child's cooperation during mealtimes, improves their overall mood, and reduces caregiver stress regarding their child's feeding difficulties (Adams et al., 2012).

The institution Solyluna is one of the few paediatric rehabilitation centres in the city of Merida (Mexico) that provides multidisciplinary services to children with a variety of physical and behavioural disabilities. To continue providing high-quality healthcare with a specific focus on achieving long-term goals for patients with CP at therapy centres like Solyluna, telehealth is emerging as a promising platform. Telehealth may especially be relevant as challenges for these patients and families are intensified by school closures, crowding at home, and decreased access to healthcare and therapies.

Due to various restrictions, many children with CP stayed home, away from the daily treatments and services provided in rehabilitation schools and clinics, especially if they suffered from comorbidities such as pulmonary disease or elevated blood pressure.

Previous studies have highlighted the potential for internet interventions to serve as a cost-effective alternative to caregiver support (Ben-Pazi et al., 2020; Dam et al., 2017), but it is important to underline that it cannot completely substitute face-to-face services.

The internet and telecommunication era has transformed healthcare into a more accessible and collaborative model, but one of the biggest challenges with telehealth is transitioning and adapting patients and their families from in-person visits to technology-dependent meetings. The existing telehealth guidelines indicate that any smart device with a built-in camera (e.g., phones, tablets) and Internet access is adequate as long as it can support the necessary software. In most parts of the world, such devices are vastly more available, but practitioners may still encounter families and caregivers who do not have access to this hardware, or to adequate Internet speed. Lerman et al. (2020) developed a guideline concerning remote coaching of caregivers, in which they suggest that practitioners instruct caregivers to resolve software issues with a phone call or via graphical instructions through screenshots, and in some cases, they suggest caregivers/practitioners seek out assistance from a technology professional.

The participants reported that OMOP helped them understand the feeding and swallowing process, as well as the basics of oral motor treatment and the necessary adjustments needed to be made during mealtime. But given the exploratory nature of the implementation, we should be cautious when interpreting the preliminary results. The main purpose of Stage 4 was to test the content and terminology used to better suit the target population in terms of comprehension and interest.

Although attendance was identified as an important implementation challenge, the present study was not designed to examine the association between participant attendance and satisfaction with the program. Future implementations should systematically monitor session attendance to better understand its influence on participant engagement and program delivery. The absenteeism rate was high, but it provided valuable guidance to modify the strategy to promote adherence to the program. Changes made include adjusting the OMOP schedule to the school calendar, inviting participants interested in FSD management regardless of the diagnosis of their child, and providing equal time to the theoretical and practical sessions. The most challenging aspect of the online program developed is the practical training, given that the participants have to learn how to perform the exercises with a mannequin following the instructor's guide through an electronic device.

One possible explanation for the high rate of absenteeism is that some caregivers may have perceived the OMOP as an informal healthcare service, resulting in a lower level of commitment than typically associated with routine face-to-face rehabilitation sessions. Therefore, future implementations should place greater emphasis on increasing caregivers' awareness of the importance of active participation in the rehabilitation process. We discussed strategies to engage caregivers and handle common problems using online communication tools (e.g., WhatsApp) to make them feel motivated and accompanied for future implementations of the OMOP trial. For example, Rimmer et al. (2018) implemented some strategies to prevent dropouts in their study that was about the design of a telerehabilitation intervention for adults: the participants who missed a scheduled session and more than 2 consecutive self-monitoring time points were contacted by staff and re-engaged. Nowadays, the free and accessible apps for mobile devices present useful features that allow health professionals to contact and monitor caregivers in group chats with less effort, which eases the communication process. The high rate of absenteeism observed during the preliminary implementation provided important information for refining the delivery strategy of the program.

The constant practice of the treatment requires increased time during the feeding routine, which could represent a challenge for the parents who already have many time-

consuming duties to fulfil secondary to the special needs of their child. However, it is expected that the health benefits experienced by the child with CP due to improved caregiver feeding practices would, in turn, reduce the amount of time the parent spends caring for the child during meals.

The preliminary implementation of telehealth programs using small samples is common during the early stages of intervention development. A previous pilot study consisting of a family-focused tele-intervention for children with developmental coordination disorders involved the development of prototype materials, trialling and processing evaluations with only 3 children and their families, refining of the program and then another trial was conducted. This study yielded positive outcomes, and challenges were also able to be identified (Miyahara et al., 2009). The next stage of this research will be to evaluate the program in a larger pilot implementation study.

The final program consisted of 8 hours in sixteen 30- minute sessions. This modification was pertinent because it is important to not only perform the exercises correctly but also to have an understanding of the physiological patterns that sustain the therapy method, especially because the caregiver is going to be in charge of the entire home treatment (feeding positioning, cutlery adaptation and passive exercises).

One last modification in the program is the inclusion of caregivers of children with other diagnoses apart from CP that are also affected by FSD. The literature affirms that regardless of the aetiology or severity, disruptions in the feeding and swallowing process may result in an increased burden to the caregiver, social restriction, and diminished quality of life. But an intensive interdisciplinary approach has been shown to significantly improve caregiver stress and child outcomes no matter the child's medical and feeding history (Arvedson et al., 2010; Greer et al., 2007). The opportunity for a larger sample size consisting of children, families, and caregivers that attend the rehabilitation centre regularly could increase the chances of recruitment and retention.

It is important to note that although telehealth and online services might be perceived as a universal solution for bringing health services to children and families despite their location or schedules, the current scenario is far from being perfect and accessible for everyone. Mexico, as a developing country, has a high rate of poverty, and consequently, families that are already struggling with the lack of access to basic services such as health, social security, education and nutritious food are going to find it more difficult to join telehealth.

Finally, an important aspect to consider when looking at the population of this study is that in Merida and other communities in Yucatan (Mexico), a significant number of people speak the indigenous Mayan language as an exclusive way of communication. Others speak a mix of Spanish and the Mayan language. Unfortunately, a limited number of health professionals are able to speak both Spanish and Mayan, so even if the Mayan-speaking families find access to an Internet device, the language barrier could present a significant hindrance to their care.

Limitations of the study

This study has a number of limitations. First, it was conducted at a single paediatric rehabilitation centre, therefore limiting generalizability beyond the caregivers who attend there. Ethical considerations also meant that a conventional non-treatment control group could not be used. Although sample size is not a drawback for the first four stages, the final evaluation of the program would have benefited from a larger sample allowing statistical testing. Subsequent trials may test the efficacy of the program in participants from other therapy centres in the city and rural areas, and perhaps, with caregivers of children with other related diagnoses. Given the benefits of telehealth, a growing number of practitioners are likely to incorporate this modality into their clinical services. Nonetheless, reviews of research on telehealth-based services, including remote coaching of caregivers

via video conferencing, suggest that the empirical basis for this approach is still in the early stages (Tomlinson et al., 2018).

Because this study was designed as a development and preliminary implementation study, standardized baseline assessments of caregivers' knowledge and skills, children's oral-motor function, and clinical outcome measures were not collected, as these were beyond the scope of the study. Although such information was not required to achieve the developmental objectives of the present work, future feasibility and effectiveness studies should incorporate standardized assessments of caregiver competencies, children's feeding and oral-motor function, and clinical outcomes to better characterize participants and evaluate the impact of the intervention.

The satisfaction survey was used as a formative evaluation tool to guide program refinement. Although the main themes identified from participants' responses are reported, item-level response frequencies were not systematically recorded. Future implementations should include quantitative reporting of satisfaction responses to facilitate more detailed evaluation.

These initial results encourage further research, taking into account the above-mentioned amendments to the OMOP and recruiting more participants so group comparisons and statistical significance of the results can be explored. The content of the OMOP could later be implemented either exclusively online or in combination with face-to-face sessions, a topic worth exploring.

CONCLUSIONS

The present study describes the successful development and preliminary implementation of an online caregiver training program for children with feeding and swallowing disorders. The content development and the feedback from participants suggest that an online program may represent a feasible and accessible approach to train and support caregivers in delivering oral-motor therapy at home for children with CP or any FSD. This development model may serve as a practical framework for designing similar telehealth-based caregiver training programs in other pediatric rehabilitation settings, particularly in contexts where access to specialized services is limited. By facilitating continuity of care and empowering caregivers through structured training, this approach has the potential to contribute to more accessible family-centered rehabilitation services. Further research is needed to evaluate the feasibility, acceptability, and effectiveness of the program in larger populations, as well as its impact on participant recruitment and retention, caregiver competencies, child health outcomes, and long-term implementation in routine clinical practice.

DECLARATION

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