





Responsive and integrative assessment and intervention in children with pediatric feeding disorder with Trisomy 21: A case report

Avaliação e intervenção responsiva e integrativa na criança com distúrbio alimentar pediátrico com Trissomia do 21: Relato de caso

Evaluación e intervención receptiva e integradora en un niño con trastorno alimentario pediátrico con Trisomía 21: Reporte de caso

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Abstract

In children with Trisomy 21 feeding difficulty can be observed, such as changes in oral motor skills, sensory processing, longer mealtimes, food refusal, lack of autonomy and others. However, there is little discussion about feeding difficulties and rehabilitation process in this population. This study aimed to

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describe speech-language and occupational therapy assessment and intervention in feeding difficulties in a 3-year and 2-month-old male child with a diagnosis of Trisomy 21. Speech-language pathology assessment found that the child had feeding difficulties, delay in oral motor skills, low intraoral perception and acceptance, while the occupational therapy assessment showed an altered sensory profile. The speech-language pathology sessions included aspects such as food perception, rhythm and feeding time. In turn, occupational therapy sessions aimed to adjust the alertness level, promote independence and psychomotor development. After the intervention, the speech-language pathology reassessment showed that there was an expansion of the menu for the ingestion, improvement in perception and intraoral motor skills, acceptance of different utensils and food presentation modes, autonomy and pleasure in meals. The reassessment of occupational therapy showed a better level of alertness and attention, more functional use of hands and fingers to eat. Therefore, a positive progress was observed in the feeding difficulty of a child with Trisomy 21 after a speech-language pathology and occupational therapy intervention with the use of responsive and integrative feeding strategies.

Keywords: Pediatric; Pediatric feeding and eating disorders; Feeding and Eating Disorders; Perception; Down syndrome

Resumo

Na criança com Trissomia do 21 a dificuldade alimentar pode estar presente. Alguns sinais são as alterações na habilidade motora-oral, no processamento sensorial, tempo elevado das refeições, recusa alimentar prolongada e falta de autonomia. Ainda pouco se discute sobre as dificuldades alimentares e seu processo terapêutico nesta população. O objetivo deste estudo foi descrever a avaliação e intervenção fonoaudiológica e da terapia ocupacional na dificuldade alimentar de uma criança com Trissomia do 21 com o uso de estratégias de alimentação responsiva e integrativa. Criança 3 anos e 2 meses, sexo masculino. Avaliação fonoaudiológica demonstrou criança com distúrbio alimentar pediátrico, caracterizado por atraso na habilidade motora-oral, baixa percepção intraoral e comportamento alimentar altamente seletivo. Na avaliação da terapia ocupacional verificou-se perfil sensorial alterado. Na fonoterapia foram trabalhados aspectos como a percepção do alimento, ritmo e o tempo de alimentação. Na terapia ocupacional, o objetivo foi adequar nível de alerta, favorecer a independência e o desenvolvimento psicomotor. Após a intervenção, a reavaliação fonoaudiológica demonstrou que houve ampliação do cardápio, melhora da percepção, da habilidade motora intraoral, aceitação de diferentes utensílios e modos de apresentação do alimento, autonomia e prazer nas refeições. A reavaliação da terapia ocupacional mostrou um nível de alerta e atenção mais adequado, uso das mãos e dedos de maneira mais funcional para se alimentar. Foram observadas evoluções positivas em relação à intervenção fonoaudiológica e da terapia ocupacional na dificuldade alimentar de uma criança com Trissomia do 21 com o uso de estratégias de alimentação responsiva e integrativa.

Palavras-chave: Pediatria; Transtornos de Alimentação na Infância; Transtornos da Alimentação e da Ingestão de Alimentos; Percepção; Síndrome de Down

Resumen

Niños con Trisomía 21, pueden presentar dificultades de alimentación. Algunos signos son cambios en las habilidades motrices orales, procesamiento sensorial, tiempos prolongados de comida, rechazo prolongado de alimentos y falta de autonomía. Hay poca discusión sobre las dificultades de alimentación y su proceso terapéutico en esta población. El objetivo deste estudio fue describir la evaluación e intervención fonoaudiológica y de terapia ocupacional en la dificultad de alimentación de un niño con Trisomía 21 utilizando estrategias de alimentación receptiva e integradora. Niño de 3 años y 2 meses. La evaluación fonoaudiológica mostró un trastorno alimentario pediátrico, caracterizado por un retraso en las habilidades motoras orales, percepción intraoral baja y comportamiento alimentario altamente selectivo. En la evaluación de terapia ocupacional se observó un perfil sensorial alterado. En fonoaudiología se trabajaron aspectos como la percepción de alimentos, ritmo y tiempo de alimentación. En terapia ocupacional, el objetivo fue ajustar el nivel de alerta, favoreciendo la independencia y desarrollo psicomotor. Después

de la intervención, la reevaluación fonoaudiológica se evidenció una ampliación del menú, mejoras en percepción, motricidad intraoral, aceptación de diferentes utensilios y formas de presentar alimentos, autonomía y placer en las comidas. La reevaluación de terapia ocupacional mostró un nivel de alerta y atención más adecuado, uso de manos y dedos de forma más funcional para alimentarse. Fueron observadas evoluciones positivas con relación a la intervención fonoaudiológica y de terapia ocupacional en la dificultad de alimentación de un niño con Trisomía 21 con el uso de estrategias de alimentación receptiva e integradora.

Palabras clave: Pediatría; Trastornos de Ingestión y Alimentación en la Niñez; Trastornos de Alimentación y de la Ingestión de Alimentos; Percepción; Síndrome de Down

Introduction

Pediatric Feeding Disorder (PFD) is the term currently used to describe cases of inadequate oral intake for age associated with some medical, nutritional, eating ability and/or psychosocial dysfunction of the child¹. This classification is based on the precepts of the International Classification of Functioning, Disability and Health (ICF), since it is correlated with the functional impacts of feeding difficulties, and can lead to participation restrictions or changes in the environments in which the child has meals (school, friend's house, trips, etc.).

Several studies have already shown that PFD may be present in different populations, including children with Trisomy 21^{2,3}. It should be noted that the early and correct diagnosis of PFD in this population can prevent the worsening of the condition and the use of coercive strategies focused only on the child's mouth.

There is little material available in the literature addressing feeding difficulties and their therapeutic process in the population with Trisomy 21. Even today, studies that investigate feeding aspects of this population focus on the rehabilitation of oral-motor skills in isolation or on oropharyngeal dysphagia, when present^{4,5}. However, there is an understanding that the eating behavior of these children is not only related to their motor-oral inability, but also to other equally important factors, such as changes in sensory processing, long meal times, refusal and or food selectivity, and lack of autonomy, among others^{4,6,7}.

Studies conducted throughout the 1990s and 2000s promoted intraoral and facial manipulation strategies aimed at optimizing the tonus and mobility of the organs involved in feeding, especially in the population with genetic syndromes, cerebral palsy and prematurity^{8,9}.

In this sense, the focus of rehabilitation in most studies was limited to the mouth and preparing it for the function of eating. When investigating beyond oral-motor issues, it is possible to notice that eating is an act that needs to be learned and, as such, requires intrinsic motivation, curiosity, comfort and the ability of the subject who is eating. It can also be noted that this learning depends on the opportunities offered by the environment, the beliefs and emotions of the learner and who feeds them¹⁰.

In this context, there are new proposals for action that have been presented to address the challenges involved in food in a responsive and integrative way^{11,12}. Given that PFDs are complex and have different diagnoses and symptoms that impact the overall health of the child, a therapeutic process carried out by an integrated transdisciplinary team is as essential as the strategies used for the intervention. In this sense, the work of speech-language pathologists should go beyond the treatment of orofacial motricity alterations, also investigating the quality of meals, food pleasure, interest and motivation of the child, so that there is a responsive and transdisciplinary intervention.

Based on the complexity of learning to eat, this case report aimed to describe the speech-language pathology and occupational therapy assessment and intervention in the pediatric feeding disorder of a child with Trisomy 21 using responsive and integrative feeding strategies.

Presentation of the clinical case

This study was approved by the Research Ethics Committee under the No. 08120218.7.0000.55, and it was conducted at Children Development Institute, São Paulo, Brazil. All subjects (or their guardians) signed the Informed Consent Form (ICF). This institution specializes in caring for



children diagnosed with PFD and has a transdisciplinary integrative care flowchart.

This case report describes the case of a male child, 3 years and 2 months old, diagnosed with Trisomy 21, referred to the Children Development Institute by a nutritionist due to the complaint of food refusal and difficulty in texture progression. As for the patient's medical history, the report includes a surgical approach to correct heart disease at 03 months of age, gastroesophageal reflux disease, micro aspirations and prolonged use of a nasogastric tube that later evolved into gastrostomy. According to the guardians, the child ate a small volume of whipped soup and showed interest in solid foods, despite not being able to ingest them (spitting out pieces or avoiding eating them). The child also did not participate in family meals, and he was always fed something to distract him (tablet), had nausea during the meal and, sometimes, he was forced to eat. The use of gastrostomy at this time was intended only for caloric intake.

After learning about the case and interviewing the parents, the speech-language assessment was carried out in person using foods in which the child expressed interest (water, steak and flour biscuits) with the help of usual utensils (spoon and teathers). The child's assessment found a pattern of kneading the food with posteroanterior movements of the tongue, with no lateralization movement being observed, which would be expected for this age group. The child also had efficient and safe swallowing, without clinical signs of penetration and/or laryngeal aspiration for accepted foods. In addition, the child performed intense stimulation of the oral cavity, constantly bringing objects and his own hand to his mouth, as well as large pieces of food (mouth stuffing), which indicates the need for oral stimulation.

In addition to the oral aspects, the assessment showed that the child had global motor delay, and little focus time during the proposed activities, in addition to low exploration of objects with non-symbolic games. Due to these observed aspects, the child was also referred for an occupational therapeutic assessment in sensory integration at the Children Development Institute. The occupational therapist's assessment included an interview with the guardians and unstructured clinical observation through the analysis of free play and exploration of the equipment in the room. The evaluation also included the result of the Sensory Profile¹³ question-

naire, previously answered by the family, pointing out the probable difference score in visual, vestibular and oral sensory processing. In this sense, the findings of the clinical evaluation included a delay in neuropsychomotor development, little autonomy in carrying out activities of daily living (eating, dressing, bathing, sphincter control and personal hygiene), poorly developed and poorly functional play activities without presenting symbolic play (the child performed more oral than manual exploration), low level of alertness (hyporesponsive), with little engagement and the need to take breaks to lie down and rest.

The diagnostic hypothesis of pediatric feeding disorder with sensorimotor characteristics was reached after the team discussed the case. Thus, the conduct started with the scheduled intervention once a week with the professionals working together.

The objectives of the speech-language pathology intervention were related to interrupting aversive stimuli and not using distraction or pressure strategies. In addition, the speech-language pathology intervention also defined other objectives, such as improving the relationship with food through play, improving the perception of food in the oral cavity in order to expand oral motor skills and efficiency in chewing and swallowing, promoting rhythm when food, appreciating flavors and foods in different forms of presentation (whole, broken/cut, crumbled, etc.) and promoting independence when eating.

On the other hand, the occupational therapy intervention aimed to adjust the level of alertness and activity, aiming at greater engagement and participation of the child, favoring the development of tactile perception and discrimination (body and oral), stimulating the development of schema and body awareness, stimulating more manipulative, constructive and functional play, as well as favoring independence in activities of daily living (eating).

Therapeutic strategies included playful activities of interest to the child, such as fitting objects, textured toy foods and suction cups placed on the mirror. In addition to these activities, the therapists also used vestibular stimuli (rocking), tactile and proprioceptive stimuli (strength, vibration and massage activities) in order to adjust the level of alertness. Tactile-thermal-gustatory stimulation was also performed, using water flavored with citrus fruit and textured teathers. Food was



offered throughout the session, which encouraged the placement of food in the molar region, favoring tongue lateralization and, consequently, chewing. In addition, therapists offered different forms of presentation of the same food: whole, cut, crumbled, with a finger, with a fork, with a textured spoon, etc., promoting variations in the sensory-motor-oral pattern. In addition to the work performed directly with the child, the guardians also received frequent guidance on what they should do at home.

After six months of intervention once a week, the child was reassessed by the speech-language pathologist, who found an expansion of the menu for the intake of all types of food, improvement of intraoral perception and motor skills, acceptance of spoons and forks of different sizes and ways of presenting food (whole, cut and crumbled - offered with cutlery or with hands), autonomy and pleasure in meals. In turn, occupational therapy noted more appropriate alertness and attention after specific excitatory stimulation, with improved engagement and participation in activities, improved trunk control in the sitting posture, and the use of hands and fingers in a more functional way to play and feed.

Discussion

This case report aimed to describe speech-language and occupational therapy assessment and intervention in pediatric feeding disorders using responsive and integrative feeding strategies.

In this sense, in addition to motor-oral skills, the participating child also showed complex global aspects that had a negative impact on eating. A study that compared children with Down Syndrome (DS) and children with typical development between 02 and 07 years old found that feeding difficulties were predominantly present in children with the DS and the authors also reported that the children had problems with the physical, functional and emotional aspects of eating, which is in line with our findings³. Another study, conducted by Bruni et al.¹⁴, investigated sensory processing in children with Down Syndrome between 03 and 10 years old. The result of this study suggested an atypical sensory performance in Down Syndrome, with 49% of these children showing a significant difference and 25% showing a probable difference when compared to children with typical development in their responses to sensory experiences. The

study also reported that children had significant challenges in the “low energy/weak” (69%), hypo-responsive (48%), auditory processing (43%) and tactile sensitivity (21%) categories. In this context, another study is also in line with our case report, as it also reported sensory processing problems in areas such as “low energy/weak”, hyporesponsive/sensation seeking and “auditory filtering”, correlating these findings as probable components of the behavioral and phenotypic profile of Down Syndrome. The study also reported that these issues, particularly hyporesponsiveness, seem to be related to maladaptive behaviors¹⁵.

Thus, even though this case report presents data that impacted the child's eating development, it should be noted that after 6 months in integrative and responsive therapy, the child showed positive results in relation to eating. As reported, there was an adjustment in the level of alertness, attention, posture control, and improvement in intraoral perception and motor skills. Other outcomes that showed improvement include acceptance of spoons and forks of different sizes and ways of presenting food (whole, cut and crumbled - offered with cutlery or hands), autonomy and pleasure in meals.

Unfortunately, however, there are still few publications investigating PFD. Many studies on feeding have focused on isolated oral-motor skills, or even, oropharyngeal dysphagia^{4,5}. However, the complexity of the PFD and all the responsive and integrative approaches needed to intervene in the feeding of these children must be highlighted. Silva et al.,¹¹ reported that responsive eating should be more valued and that health professionals should guide families on how to practice it, which requires them to go beyond more general issues in relation to eating. The authors stated that it is necessary to try to understand the sociocultural insertion and the psychosocial aspects of the family in order to provide personalized guidance. With regard to the multidisciplinary intervention, a study with a systematic review design proved that the involvement of several areas of expertise provides important contributions when designing the PFD intervention¹².

Finally, the field of study related to PFD still requires research with robust methodological designs that describe the evaluation and therapeutic process for better identification of signs and adequate transdisciplinary management/intervention. Therefore, it is essential to integrate and evaluate



sensory, motor, motor-oral, behavioral, medical, nutritional, emotional, environmental and family areas in order to rehabilitate PFD.

Final considerations

This case report allowed evaluating the described positive developments associated with speech-language and occupational therapy intervention in the feeding difficulty of a child with Trisomy 21 with the use of responsive and integrative feeding strategies.

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