

# From dysphagia to food restriction: effects of parental adaptation to the daughter with congenital blindness

Da disfagia à restrição alimentar: efeitos das dificuldades de adaptação parental à filha com cegueira congênita

De la disfagia a la restricción alimentaria: efectos de las dificultades de adaptación de los padres a la hija con ceguera congénita

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## Abstract

**Introduction:** The birth of a child with a disability can change routines and influence the parents' adaptation process, as it is characterized as an unexpected event. It can still produce similar feelings in parents as those experienced in a grieving process. **Objective:** To analyze the relationship between parental adaptation to the daughter with congenital blindness and dysphagia, related to extreme prematurity, and its possible impact on the process of adherence to therapeutic guidelines on child nutrition. **Method:** This is a qualitative case study. An analysis of parental adaptation to disability as well as language therapy assessments of language and dysphagia were performed. **Results:** The speech therapy evaluation showed dysphagia for fine liquids and absence of language disorders. Dietary restriction became evident from the parental difficulty in accepting and following the guidelines regarding food consistency. The analysis of the parental adaptation data to the daughter's disability suggests that this difficulty was related to the

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RSB: conception and writing of the article.

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acceptance of blindness and dysphagia. The emergence of food restriction was related to the difficulties in parents' acceptance of speech therapy guidelines, considering dysphagia for thin liquids. These difficulties find a correlate in the analysis of the father and mother's parental adaptation. **Conclusion:** The importance of monitoring by an interdisciplinary team is evident.

**Keywords:** Prematurity; Dysphagia; Blindness; Psychological Adaptation; Interdisciplinary Health Team.

## Resumo

**Introdução:** O nascimento de um filho com deficiência pode alterar rotinas e influenciar no processo de adaptação dos pais, por se caracterizar como um acontecimento não esperado. Ainda pode produzir nos progenitores sentimentos semelhantes aos vivenciados em um processo de luto. **Objetivo:** Analisar a relação entre a adaptação parental à filha com cegueira congênita e disfagia, relacionadas à prematuridade extrema, e seu possível impacto no processo de adesão às orientações terapêuticas sobre a alimentação da criança. **Método:** Trata-se de um estudo de caso de cunho qualitativo. Foi realizada uma análise da adaptação parental à deficiência, e avaliações fonoaudiológicas da linguagem e da disfagia. **Resultados:** A avaliação fonoaudiológica evidenciou disfagia para líquidos finos e ausência de alterações de linguagem. A restrição alimentar tornou-se evidente a partir da dificuldade parental em aceitar e seguir as orientações quanto à consistência alimentar. A análise dos dados de adaptação parental à deficiência da filha sugere que essa dificuldade esteve relacionada à aceitação da cegueira e da disfagia. A emergência de restrição alimentar esteve relacionada às dificuldades na aceitação das orientações fonoaudiológicas por parte dos pais, considerando a disfagia para líquidos finos. Essas dificuldades encontram um correlato na análise da adaptação parental do pai e da mãe. **Conclusão:** Evidencia-se a importância do acompanhamento por uma equipe interdisciplinar.

**Palavras-chave:** Prematuridade; Disfagia; Cegueira; Adaptação Psicológica; Equipe Interdisciplinar de Saúde.

## Resumen

**Introducción:** El nacimiento de un niño con discapacidad puede cambiar las rutinas y estilos de vida de los padres, ya que se caracteriza por ser un evento inesperado. Todavía puede producir sentimientos similares en los padres a los que experimentaron en un proceso de duelo. **Objetivo:** Analizar la relación entre la adaptación de los padres a la hija con ceguera congénita y disfagia, relacionada con la prematuridad extrema, y su posible impacto en el proceso de adherencia a las guías terapéuticas en nutrición infantil. **Método:** Este es un estudio de caso cualitativo. Se realizó un análisis de la adaptación de los padres a la discapacidad y la evaluación del habla y el lenguaje de la disfagia. **Resultados:** La evaluación de logopedia mostró disfagia por líquidos finos y ausencia de trastornos del lenguaje. La restricción dietética se hizo evidente por la dificultad de los padres para aceptar y seguir las pautas con respecto a la consistencia de los alimentos. El análisis de los datos de adaptación de los padres a la discapacidad de la hija sugiere que esta dificultad estaba relacionada con la aceptación de la ceguera y la disfagia. La aparición de la restricción alimentaria se relacionó con las dificultades en la aceptación por parte de los padres de las pautas de logopedia, considerando la disfagia por líquidos diluidos. Estas dificultades encuentran correlación en el análisis de la adaptación parental del padre y la madre. **Conclusión:** Es evidente la importancia del seguimiento por parte de un equipo interdisciplinario.

**Palabras clave:** Prematuridad; Disfagia; Ceguera; Adaptación Psicológica; Equipo de Salud Interdisciplinario.

## Introduction

Considering that feeding difficulties in children account for a wide range of problems from their start<sup>1</sup> and that the first thousand days of a child's life are fundamental from a nutritional point of view<sup>2</sup>, there has been a great deal of concern when a child is at the limit of weight gain and presents an evident food restriction problem in the first years of his or her life. A complex combination of medical, sensory-motor, and behavioral factors is involved in situations of dietary restriction. Among biological problems, pediatric dysphagia without adequate speech therapy and nutritional care can be a contributing factor to the emergence of serious dietary restrictions that endanger a child's health<sup>3</sup>.

Premature birth, in particular, is among the factors that can generate major eating problems<sup>4,5</sup>. The association between respiratory problems and pediatric dysphagia, often underdiagnosed, is also common, because bronchiolitis is often associated with a risk of dysphagia in infants<sup>6</sup>. Due to serious biological limitations and nutritional risks, some children require tube feeding. In these cases, parental stress management is crucial, which in turn shows that a child's eating difficulties have significant effects on parental care<sup>7</sup>.

Parental care becomes an even greater challenge when eating problems are part of a disturbance that affects visual processing, which is one of the fundamental systems of the human body. This is because expectations about the child, built by the parents all during the pregnancy, may not materialize. It is known that even children who do not have any type of disability may not correspond to the parents' expectation; however, when the child has a disability, this disappointment may be even greater. If reidealization does not take place, allowing the parents to bond with the child who was born and accept his or her limitations, this can hinder child development<sup>8-9</sup>.

The presence of a child with congenital blindness, followed by other complications, can alter family routines and lifestyles<sup>8</sup>. Blindness is a visual impairment characterized by the impossibility of accessing information through vision, thus requiring adaptations by the subject and their guardians. With the impossibility of discovering the world visually, other senses will have to be used, such as hearing, touch, smell, taste, and the kinesthetic

system. When vision loss occurs before the age of five, it is called congenital blindness<sup>10</sup>.

The birth of a child with disabilities is experienced by parents as a crisis, and several different emotions may be felt at that moment, such as revolt, denial, and guilt, in addition to depressive feelings<sup>9</sup>. These feelings are considered as the first emotional responses to the loss of the parents' idealization of their baby, leading to a process of mourning their idealized child. Parents who cannot experience this mourning encounter obstacles to connect emotionally with the child, and may adopt a functional attitude, i.e., they become action-oriented, instead of building a true parental connection to their child. Some may still remain in a state of denial and revolt<sup>11</sup>.

The process of parental adaptation does not end by just going through the mourning period, but by reidealizing their child. It is necessary that, from the moment of birth and/or when first hearing about the child's disability, parents be guided toward the emergence of a desire of investing in their child. This reidealization represents the possibility of investing emotionally in the real baby, and of thinking about what he or she actually is and might be like, and not what he or she could have been like. Thus, it is through reidealization that the family can resume their development process with the child who has a disability<sup>11</sup>.

In view of the aforementioned, the aim of this article is to analyze the relationship between parental adaptation to their daughter with congenital blindness and dysphagia due to extremely premature birth (born at 30 weeks of gestation) and its possible impact on the process of adherence to dietary guidance. It is worth mentioning that the child's dysphagia is a sensory one, stemming from her clinical condition.

## Method

The analysis conducted in this article consists of a description of the data and an interpretation that seeks to explain the relationship between the characteristics of parental adaptation to Lara (fictitious name), who has congenital blindness and dysphagia for thin liquids. Congenital blindness resulted from retinopathy associated with extremely premature birth. Lara was diagnosed with dysphagia at the age of three, by means of a clinical evaluation of her swallowing, and the diagnosis was confirmed

at the age of four, through a videofluoroscopic swallow study. As a result of her dysphagia, she developed a dietary restriction condition that put her at nutritional risk.

This case study is part of the research project Validation of the Parental Adaptation to The Child with Disability Scale (EPAD, in the Portuguese acronym). This instrument, which identifies the process of parental adaptation to their child's disability, was approved by the research ethics committee under process number 3.073.809 and CAAE 02809718.2.0000.5346 in the higher educa-

tion institution to which the authors belong. Lara's parents responded to the EPAD after signing the Free and Informed Consent Form, whereby they agreed with the conduction and publication of the research and its results.

Among the procedures included in this analysis are the parents' responses to the EPAD<sup>12</sup> during an interview conducted by a psychologist. This occurred only once when Lara was 6 years old. The EPAD<sup>11</sup> consists of 30 items across a development scale, with two factors and five dimensions, as described in Chart 1.

**Chart 1.** Structure of the Parental Adaptation to the Child with Disability Scale - EPAD

	Factors	Dimensions	items	Maximum value
Development	REIDEALIZATION	AESTHETICS	6	30
		ABILITIES	6	30
		FUTURE	6	30
		RESILIENCE	6	30
		SUPPORT	SOCIAL SUPPORT	6
Total				150

Lara's parents responded to the items using the Likert scale, which aims to measure the subjects' responses. These answers vary according to the degree of agreement or disagreement with the five dimensions (d) under study, each containing 6 questions (q), with the following possible answers:

1. I completely disagree
2. I somewhat disagree
3. I neither agree nor disagree
4. I somewhat agree
5. I completely agree

Considering that the maximum value of the scale is 150 points, we tried to make a descriptive and qualitative reading of the parents' answers. The mother's answers were compared with the father's, since the scale reference values are still under validation. It is important to note that the maximum value (M) per dimension is 30 points ( $M=d \times q$ ).

Some speech-language pathology evaluations were also performed, such as a clinical assessment of the risk of dysphagia, and initial and follow-up interviews on the clinical history from pregnancy

to the moment of collection. The focus of these interviews was on questions associated with premature birth, pulmonary issues in the first two years of life and a detailed food diary, psychomotor and language evolution, as well as the family's psychosocial and sociodemographic aspects. A videofluoroscopy was performed, which is an objective procedure that assesses the act of swallowing. Similarly, oral language was also evaluated by observing the dialogue between the girl, her therapist, and the parents. In the therapeutic setting, the therapists decided to use dialogue and play as a support approach, facilitating the understanding and the expansion of Lara's vocabulary. The food aversion was approached during the sessions by means of guidance on safe foods and how these should be introduced, as well as Lara's active participation in the process, as her visual impairment made it impossible for her to anticipate when utensils were going to be introduced in her mouth when she was fed by others.

## Case Presentation

Lara was referred at the age of three by the occupational therapy team to the speech-language pathology team at the city's university hospital due to the feeding difficulties she presented and for a language assessment. At the age of four, the speech therapist responsible for the case requested a videofluoroscopy and also a clinical evaluation by the pediatric dysphagia team, which led to the diagnosis of dysphagia for thin liquids. Dysphagia consists of any alterations that occur in the transport of the food bolus from the oral cavity to the stomach<sup>13</sup>. Thus, based on the results of the evaluations, the hospital team recommended that family members remove thin liquids from Lara's diet, and these guidelines were monitored weekly by the therapeutic team.

The occupational therapist observed, however, that the recommendations provided by the speech therapists at the hospital were not followed by family members, who kept offering thin liquids to Lara, and that Lara's breathing difficulties and/or periods when she refused to feed persisted. As a result, her weight was below what was expected

for her age, and the girl was facing nutritional risk. Lara had a history of recurrent pneumonia for the first two years of her life.

## Results

The beginning of therapy with the speech therapist from the early intervention group (the second author) was guided by the last author and allowed the therapist to realize the family's difficulty in dealing with Lara's blindness, which was due to her extremely premature birth, as well as with her dysphagia. Among the facts observed by the interdisciplinary team, it is worth pointing out that the parents did not provide Lara with a walking stick to help her walk alone, which is another sign of their denial of their daughter's disability.

The insertion of Lara and her family members in the EPAD research was an opportunity to analyze the child's physical, sensory and accessibility conditions, in addition to the parents' adaptation to Lara. The results regarding Lara's parents' adaptation to their daughter's disability are summarized in Table 1.

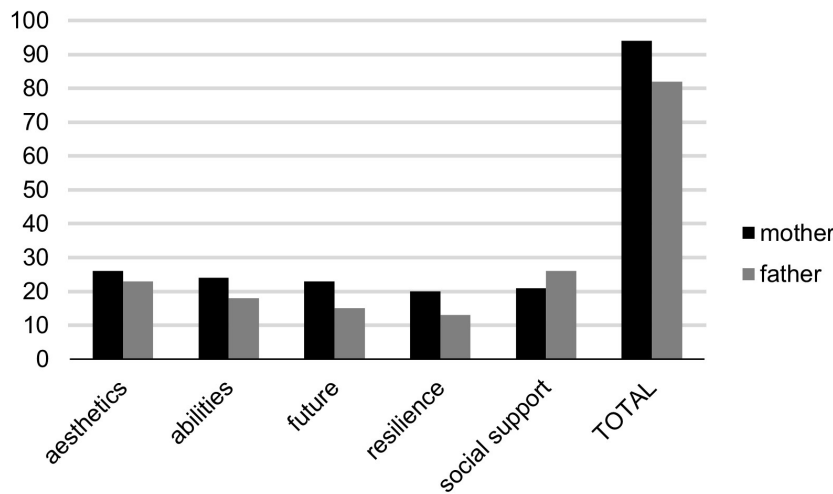
**Table 1.** Descriptive results of the Parental Adaptation to the Child with Disability Scale

Item	Dimension	Mother	Father
Everybody thinks my child is beautiful	Aesthetics	5	5
I am proud to have other people know him/her		5	5
Regardless of what others think, I think my child is beautiful		5	4
I get upset about other people's comments about him/her		4	5
I don't like people to see him/her and make comments		5	2
I like to take him/her with me to public places		2	2
TOTAL		26	23
Despite his/her difficulties, I am proud of my child's abilities	Abilities	5	5
I recognize my child's competencies		5	2
My child has certain qualities that fill me with joy		5	1
I cannot identify any qualities that are useful to him/her or to me		2	1
I can find positive characteristics in him/her		5	5
There are other less able children who seem happier		2	2
TOTAL		24	18
My child's future depends on what he/she will learn	Future	5	5
I am fully committed to helping him/her acquire the most abilities possible		5	2
When I think of the future, I don't know what to do		2	1
My child's future depends on the help the parents and technicians can give him/her		5	1
I would like him/her to one day learn an occupation		5	5
I don't think my child can be happy one day		1	1
TOTAL		23	15

Item	Dimension	Mother	Father
My child's limitations give me strength to face the situation	Resilience	2	2
My child's behaviors or attitudes help me face the future better		5	3
I have never thought I would be so strong as I have been to take care of him/her		5	1
I have become a better person thanks to my child		5	4
Ever since my child was born, I have been sadder and more depressed		2	2
I am going through unbearable suffering, largely due to his/her situation		1	1
TOTAL		20	13
My family has been a great help	Social support	5	4
My husband/wife has been a great help		5	5
I have not had anybody's help		1	5
My friends have been a great help		4	5
I have received great help from services/institutions and professionals		5	5
I feel alone caring for my child		1	2
TOTAL		21	26
TOTAL		94	82

The mother's responses remained between the minimum of 20 points (66.6%) and the maximum of 26 points (86.6%) within the dimensions, totaling 94 points (62.6%), out of a 150-point scale. The father's responses ranged between 13 points (43.3%) and 26 points (86.6%) with a total of 82 points (54.6%). It is noteworthy that both

scored more in the aesthetic dimension, and that the mother envisions more abilities and prospects for the girl than the father. She also showed more resilience, although she feels more lacking in social support than her father. Figure 1 shows the parents' comparative summary by dimension and by total score.



EPAD= Parental Adaptation to the Child with Disability Scale

**Figure 1.** Comparative analysis of the mother's and father's responses to the EPAD



The results shown in Figure 1 reflect the clinical perception in each parent's reactions to the guidance offered regarding the necessary dietary adaptations due to dysphagia for thin liquids. While the mother agreed to talk it over with the hospital's speech therapist and the outpatient therapists, the father seemed to avoid conversations about dysphagia. The mother accepted the therapists' opinions much better, and the father resisted the guidance more, sometimes insisting that his daughter drink water. During a home visit, the mother even reported an episode of serious aspiration after the father's insistence on giving Lara pineapple juice in a spoon.

We observed that Lara was more resistant to the ingestion of any food after being given thin liquids in inappropriate utensils and without warning. When, during a home visit, the speech therapists explained in detail what was happening and discussed with Lara's mother some safe glass options and the right consistency of the liquids to be offered to Lara, the child, who was present, said:

- Auntie, I'm going to drink and eat with my hand, right?

Lara's speech clearly identified that she had understood everything that had been arranged with her mother and made it clear that she got frightened by the surprise of thin liquids being placed in her mouth without her being able to develop the food narrative. In other words, due to her blindness, she could not anticipate what she was going to ingest and needed to adopt a defensive attitude when her parents insisted on giving her thin liquids, which she felt she could not swallow properly. After this home visit, the father showed a bigger commitment to the dietary recommendations as well as to the continuing therapy. Lara started drinking thickened water, and that reassured her father in regard to the child's water intake, since her hydration was his main concern.

## Discussion

Lara's birth with congenital blindness due to extremely premature birth placed her parents in an unexpected situation. In addition to the blindness, she was diagnosed at the age of four with dysphagia for thin liquids, and her parents, who had not yet dealt successfully with their daughter's original limitation, had to deal with a further issue. The birth of a child is an event that permanently alters,

transforms, and restructures the lives of parents<sup>14</sup>, especially when the child is born with a disability. It is during pregnancy that parents idealize their unborn child, who is always thought of as being healthy. Soon after birth or sometime later, when learning of their child's diagnosis, the parents are faced with a child that does not correspond to their dream. Therefore, there may be a rupture in the child's entire course of development, as well as in the family's connection with their child<sup>8,9</sup>.

The parents' response to the diagnosis given by the professionals was to deny reality, and that is part of the initial mourning process. At first, everything went on as before, with Lara's parents still giving her thin liquids. Her breathing difficulties and/or periods when she resisted feeding, and, consequently, her low weight presented the team with a challenge regarding how to deal with the case and how to understand what was happening with the family. The parents' denial was not a denial of the child's reality itself, but an attempt to deny the rupture between the baby as she was idealized by them before her birth, and the real child who was born. Parents who live in denial of their child's difficulties and wish to return to the perfect child will not be able to help them in their development. Even if they accept their child's disability, if there is no reidealization they may remain attached to the idealized child<sup>9</sup>, in Lara's case, a daughter without blindness or dysphagia. Thus, it is important that these parents can express their feelings towards their real child, so that they can deal successfully with them<sup>15</sup>.

Both the EPAD instrument and the meetings showed that each parent approached the process of parental adaptation differently. It was clinically observed that the mother was more flexible when it came to accepting the dietary guidance than the father, and that seems to be associated with the fact that she envisions more abilities in her daughter and better prospects for her. The mother was also able to talk to the team about her daughter's limitations and showed greater resilience in the face of the situation. When a family receives their child's diagnosis and prognosis, their lack of understanding, and, in some cases, denial of the special needs that the child will have may lead them to postpone the beginning of treatment. In addition, there may be an increase in the family's difficulties in caring for the child with disabilities<sup>16</sup>. In Lara's case, this was evidenced by the fact that her father continued

giving her thin liquids, and that the parents did not provide her with a walking stick so she could walk by herself.

In one of the mother's responses in the EPAD, she expressed a lack in social support. Social support networks are thought to help strengthen both children and their families, since they contribute to overcoming feelings. They can have a positive impact on improving the quality of life of both by means of increasing resilience, and also because the family cannot meet alone all the health needs and demands of their child, requiring different types of support to do so, be them emotional, instructional, or financial<sup>15,17</sup>. The support of the health team was fundamental for the family to reidealize Lara, in that it allowed the family to improve their skills, reduce their fears, and unveil their fantasies, helping them to perceive the child as a real being, thus challenging the stereotypes of a fragile figure<sup>16</sup>.

An early intervention, such as the one undertaken with these parents, is crucial to meet the needs and priorities of families and provide them with support to face emerging difficulties, in addition to minimizing the impact of the child's limitation and achieving remarkable results for both the child and the parents<sup>17</sup>. The process of reidealization can only happen once parents get in touch with their real child, and it allows parents to resume the child's development as well as their relationship with the disabled child; thus, early intervention can help accelerate the process of reidealization so parents and child may establish a solid relationship<sup>11</sup>. In Lara's case, the therapists offered support to her mother, and gradually, through her mother, they were able to also help her father accept Lara's particularities. Therefore, professionals who seek to assist parents in the processes of adapting themselves with their child with disabilities need to empathically understand the internal and emotional processes involved in the desire to be a parent, as well as these families' social and daily living conditions<sup>11</sup>.

Dysphagia affects about 8% of the world's population, and can cause malnutrition, pneumonia and dehydration<sup>18</sup>. Feeding times should be pleasurable for dysphagic patients, when the parent should respect the child's desire and comply with speech-language pathology guidance regarding the consistency of the food. In Lara's case, it is clear that the guidance on food consistency given at the first hospital visit was not enough to ensure that her feeding was successful from the nutritional and

safety points of view. It was necessary to understand the moment the parents were going through in the process of parental adaptation to disability, so that it was possible to identify the necessary measures to ensure that Lara did not remain at nutritional and pulmonary risk. This understanding is fundamental when assessing pediatric dysphagia, since there is not much time to wait for the child to be provided with much-needed, safe nutrition.

Unfortunately, it took some time for Lara to be seen by the speech therapist in the early intervention team, because the occupational therapist was slow to mention the dietary restriction. Consequently, the investigation of dysphagia began when she was three years old, because the parents were not visiting the hospital outpatient clinic regularly and resisted following the recommendations offered by the speech therapist responsible for the hospital evaluation.

This delay demonstrates the importance of effective monitoring by the interdisciplinary team and, mainly, an understanding of the parental adaptation process, in order to know whether or not the parents are capable of following the guidance offered by the health care team. Some insistence was needed on the part of the outpatient speech therapist for Lara's parents to follow the dietary recommendations. This case also shows how important it is for teams that defend the idea of one single therapist in cases of early intervention to conduct, before their decision, an in-depth, comprehensive analysis of the case to determine whether or not there are aspects that put the child at risk, be them biological, such as dysphagia, or psychological, such as parental adaptation. Interdisciplinarity was what took Lara out of pulmonary risk, and its lack at the early stages of her therapy was what put her at risk.

## Conclusion

The case of Lara, a girl with congenital blindness and diagnosed with dysphagia, demonstrated the parents' difficulties in adapting to their disabled child, as well as in accepting the dietary recommendations provided by speech therapists during the process of dysphagia evaluation and therapy. This case study indicated the importance of an interdisciplinary team from the early stages in the child's care, with effective communication between the hospital team and the therapeutic reference team.





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