Speech therapy recommendations for mothers of babies with heart disease: some perspectives

Recomendações fonoaudiológicas para mães de bebês cardiopatas: algumas reflexões

Recomendaciones de terapia del habla para las madres de niños con enfermedades del corazón: algunas reflexiones

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Abstract

During the implementation of a Speech Language Pathology and Audiology program in a shelter house for cardiac children in the city of São Paulo, maternal demands related to different aspects of development and difficulties inherent to this treatment context where identified. This speech language and hearing program was constituted by different actions, mainly in a preventive way, aiming essentially to children language development and feeding behavior, from the mother's questions and guidance demands. These demands, beside the observations made, led to the formulation of a set of recommendations for

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mothers of cardiac children which aimed to contribute to the effectiveness of mother/child interaction in this context, with views to minimize risks for child development.

Keywords: Speech Language Pathology and Audiology; Language; Child development; Child guidance.

Resumo

Durante a aplicação de programa fonoaudiológico em uma casa de acolhimento para crianças cardiopatas na cidade de São Paulo, foram identificadas demandas maternas ligadas a diferentes aspectos do desenvolvimento infantil e ao enfrentamento de dificuldades inerentes a esse contexto de tratamento. Este programa foi constituído por diferentes ações, principalmente de caráter preventivo, objetivando essencialmente o funcionamento da linguagem oral e a alimentação das crianças, a partir das perguntas e demandas de acolhimento das mães. Tais demandas, aliadas às observações realizadas, levaram à elaboração de um conjunto de recomendações para mães de crianças cardiopatas; as quais visam contribuir para a efetividade da interação da díade mãe/criança nesse contexto, de maneira a minimizar riscos para o desenvolvimento infantil.

Palavras-chave: *Fonoaudiologia; Linguagem; Desenvolvimento Infantil; Orientação infantil.*

Resumen

Durante la ejecución de un programa fonoaudiologico en una casa de acogida para los niños con enfermedades del corazón en São Paulo se identificaron demandas maternas relacionadas con diferentes aspectos del desarrollo infantil y con el afrontamiento de dificultades inherentes a este contexto de tratamiento. Este programa de intervención consistió en diferentes acciones, principalmente de carácter preventivo, visandoesencialmenteel funcionamiento del lenguaje oral y la alimentación de los niños, a partir de las preguntas y demandas de acogida de lasmadres. Tales demandas, aliadas a las observaciones realizadas, llevaron al desarrollo de un conjunto de recomendaciones para las madres de los niños con enfermedades del corazón que objetivaran contribuir para la eficacia de la interacción entre ladíada madre/hijo en este contexto, deforma a minimizar los riesgos para el desarrollo infantil.

Palabras clave: *Fonoaudiología; Lenguaje; Desarrollo infantil; Orientación infantil.*

Introduction

Recently, a debate has arisen in the field of speech therapy regarding speech, verbal, and feeding problems[1] in children suffering from chronic congenital or acquired diseases[2]. In other fields, it has long been known that these types of problems adversely affect the general development of children[3,4,5].

In this study we report our experiences involving specific speech therapy actions undertaken in a residential home that cares for children with heart disease, in the city of São Paulo, Brazil. We highlight certain findings in order to strengthen the debate in the field of speech therapy, and to bring it at par with the debate taking place in other fields of knowledge.

Heart disease frequently requires emergency treatment. However, emergency treatment is not always accessible as specialized medical centers are only located in certain regions of the country. Thus, a child suffering from heart disease must often travel to a hospital, accompanied by the mother. The journey can be long or short depending on the kind of problem and its seriousness, as well as the type of treatment required. In this context, the so-called care homes have been set up.

Children who live far from patient care centers stay in these care homes until their treatment (medication only, surgery, or organ transplant) is concluded. They return to these homes periodically for evaluations and follow-up.

The house in which the present experience took place was organized to resemble a conventional family home with typical room divisions and furniture. The daily routine was organized to maintain a

familiar schedule and minimize the effects of being away from home, both for the child and the mother.

Several activities were conducted on a daily basis: meeting for meals; support workshops for the children and their mothers (sewing, painting, theatre, etc.); tutoring for children of school age; nutritional counseling; and psychological and speech therapy counseling. In summary, there was a seemingly adequate setting to provide care for children with heart disease.

In principle, heart disease does not constitute a direct risk for the development of language or appropriate feeding function. Why, then, should we assume a scenario in which the development of these functions will be compromised in these children?

Heart diseases in children may be congenital or acquired, and the incidence is eight to 10 per 1,000 children. Surgical treatment is frequently provided[6,7].

Congenital heart diseases result from abnormalities in the structure or function of the heart as a result of changes taking place during embryonic development. Signs and symptoms appear in the first year of life and are sometimes identified during the gestational period. Interventricular communication problems occur frequently in acyanotic anomalies and in Tetralogy of Fallot (cyanotic).[6,7] In these cases, early diagnosis is important owing to the child's rapid clinical deterioration and high mortality index.

Acquired heart diseases usually appear at around four years of age, most frequently caused by rheumatic diseases affecting the heart valves[6,7].

The most frequent symptoms presented by children with congenital heart disease are weak cry; tiredness and intense perspiration while breastfeeding; poor weight gain; and continuous groaning, signaling great respiratory discomfort[6,7].

Heart disease damages the harmony between the real and the imagined: the disease dispels the desired image of the baby during feeding. Breastfeeding, usually a pleasurable and celebrated activity, becomes a source of anguish owing to the symptoms mentioned above that occur during suction. As time progresses the child's difficulty in gaining weight proves that nutrition is insufficient.

Under these circumstances, there is a tendency to over-protect the child, because of the conditions imposed by the heart disease2,8 which can affect both speech and feeding abilities in many of these children.

As a rule, all family members tend to take excessive care of these children in an attempt to protect them from the risks of the disease and to alleviate their suffering.[8] Over-protection is a predictable consequence of the adverse life conditions of a child suffering from cardiac disease, and is reinforced from the start, at every moment. Such adversities may weaken the bond between the child and mother, thus creating an obstacle in the child's development. Disturbances (more or less significant) become evident, perhaps as a consequence of inhibitions caused — among other factors — by such over-protective behaviors.[2,6]

Such over-protective behavior differs from the mother's natural protection towards the child, as explained by Winnicott[.9] who points out that the mother's job is to gradually lower the child's expectations regarding her capabilities, whereas over-protection creates a disturbed bond in the sense that the adult tends to perform actions that should be performed by the child, inhibiting the child's development.

Like the child, the mother is equally constrained owing to a fear of the disease, anguish regarding treatment, being away from home, the absence of family members and above all, the uncertainty of the future. These are inevitable predicaments, despite the efforts of the home care administrators and the teams of health and education professionals responsible for each case.

The chronic nature of the clinical picture and the treatment conditions made available by the country's health system creates a considerably unfavorable situation for the development of the child, requiring specific care actions, including speech therapy.

Description

Many small children who stay at the care home for treatment present with different types of speech impairments. This has created the need for specific speech therapy techniques to be developed for them that aim not only to improve speech, but also to prevent future problems with writing.

Many of the mothers sought interviews with professionals to discuss their difficulties in dealing with their children, particularly regarding the feeding issue.10,11 An issue that was not

included in the original work plan therefore became an object of concern and specific action: the concerns of these mothers. We identified the mothers of the children staying in the care home. There were 16 babies undergoing treatment; ten of them were already at the stage of release, following surgical and/or medication treatment.

All the mothers were invited to an individual meeting, with the purpose of identifying their individual concerns. Each mother spoke freely in a manner consistent with her needs, wishes, and personal style.

From their testimonies, we learned that the mothers were affected by the risks, damage, and difficulties related to the disease and they felt anguish when dealing with their children. Such testimonies were examples of a conflict between the hope of a cure (partial or total) and concern about how to care for their children. Some babies would be still for a long time but were still fragile and required extensive care. At the end of the treatment, they were returning home with a child who survived but was still very delicate.

The mothers' challenges mainly concerned feeding and language issues; they frequently referred to the silent behavior they observed in their babies.

The recommendations presented here resulted from discussions concerning these demands, and aimed to suggest attitudes and situations that could promote the children's development. The promising nature of these recommendations is based on the uniqueness of each developmental process [12] .The recommendations aimed to contribute towards the efficiency of the mother/child interaction and subsequently to adequate stimulation, with a view to develop each child's "oral" skills (verbal and feeding), the main maternal concerns.

The mothers also had questions about how to play with their babies, associated with a fear of touching the child's thorax and causing undesirable effects (pain, discomfort). In summary, it seems that these risks limit interaction and the mother/child bond becomes frail.

As previously mentioned, problems with feeding and breast-feeding – paramount functions because they are linked to the child's survival – constitute the main symptomatic spectrum of heart diseases during infancy. Establishing and maintaining the mother-baby relationship is at risk, as feeding (nursing) is precisely the context in which the mother-baby relationship first develops.

This circumstance led to an initial question: does the mother-child bond, which becomes weakened during the risk situation, become naturally strong again after the child is released from treatment? Or does it have to be re-established?

Studies on child development have shown that this relationship must be re-established. It is almost as if the child, now as an individual free from the risk of death and, therefore potentially promising in his/her capacities and abilities needs to be re-introduced to the mother[13.] This point became the cornerstone of the intervention and represented the first assumed decision: re-enact the bond for adequate development.[14,15]

The next step was to determine how to develop a study to assess the mother-child bond. Research on child development led to the outline of the following guidelines concerning maternal conduct.

The first was to assume that the child would develop normally. This attitude was named the "anticipation process"[16,17] meaning the way in which the mother imagines reality.[16,17] She acts "as if" the baby could talk, walk, and perform many other things. Acting "as if" becomes instituted in the discourse, a basis for the bond between the mother and her child.

We decided to start by encouraging the use of "mommy speech" in the communication with the child, since what creates the bond in the beginning is the intonation of the maternal voice - music without lyrics, as described by Jerusalinsky[12]. In "mommy speech," the mother creates a listening space for the child, and being listened to is an essential condition for speaking[16.] In addition, "mommy speech" is characterized by an ascending melodic curve based on the assumption that the child "will speak," creating a space for the child to communicate.

Surrounded by "mommy speech", symbolical practices (feeding, cleaning, sleeping, playing) develop, and the child's "bonding" with the other person is reaffirmed[17]. Such symbolical practices are characterized by spontaneity, since replacing the spontaneity of the mother-child relationship with recommendations of a training program would give rise to robots instead of children[19]. Using a pleasing voice[20], choosing delicate words in rhythmic contexts and songs with repeated lines[21,22], and constant playing[12,22] help to achieve the desired goal.

The second recommendation was to avoid over-protecting the baby even though he/she is vulnerable because of the disease and the treatment itself, which can cause delays in the developmental process. Over-protection creates inhibitions, leading to atypical developmental outcomes.

Based on the literature, we decided that explanation regarding this problem was needed. We identified evidence indicating that what is important is to allow the children to become autonomous,[12] i.e., delimiting their behaviors: letting them do what they can do, helping them with what they cannot do, and teaching them what they do not know.

At first the recommendations concerned the mother-child bond and subsequently they addressed the language and feeding issues.

Two aspects stood out in the recommendations regarding feeding. The first included the food's texture, quantity, quality, and temperature. The second derived from the first, and pertained to the food's seizing, mastication, and deglutition. It is worth keeping in mind that these babies have always had problems with these procedures, as a consequence of the dyspnea associated with heart disease.

Regarding language, the recommendations were defined by the use of "mommy speech" as previously mentioned. Another important factor was to point out the need to speak to the child, a pre-requisite for the child to begin talking. The two best settings for talking to a child are during care (feeding, cleaning, and sleeping) and play situations.

Finally, a few more recommendations were introduced regarding typicality indexes, aimed at guiding the mother in supporting the development of the baby.

Playing was approached in two different ways. First, we discussed the limitations imposed on the child by the treatment, and the medical or nursing recommendations, which needed to be followed and, if in doubt, clarified. Second, we introduced/dramatized three types of play that are fundamental for development: hide and seek, assemble/disassemble and "as if." [12]

The tool used in the interventions is presented in the Appendix 1. It is a text "guide" used to instruct each of the mothers.

In almost all cases, this instruction was performed in a single session, on the day before the child left the care home. The duration of these sessions varied from one to two hours, depending on the needs and conditions of each mother. In only two instances, the sessions were performed during the last week of the stay in the home and required more than one meeting. The repetition of the session was performed because of the mothers' desire to report on the importance of the guidance and express their satisfaction, rather than because of new concerns.

During the instruction, the speech therapist explained the development of each skill (eating, speaking, and playing) and proposed daily routines that could stimulate the child. At the end of the session, the mother was invited to discuss the work performed.

All mothers expressed satisfaction and interest in the topics discussed during the session, indicating that the professionals selected the right themes and presentation style. Nearly all mothers requested the "guide text" from the professionals, claiming it was a safe source of instructions/suggestions for baby behavior. The professionals specifically warned the mothers that a strict or radical interpretation and/or use of the text might not work as a stimulant for development, but as an obstacle to understanding the singularities of each child.

Final Considerations

The organization of these recommendations derived from the concerns expressed by the mothers of children with heart disease. The aim was to minimize the risks to the infants' development as a consequence of treatment, especially regarding oral language and feeding functions.

The guidance had a positive effect, in the sense that the mothers were very receptive to the proposals.

This experience suggests that such procedures should be further investigated and extended to other clinical risk conditions (not restricted to heart diseases), and especially congenital disorders.

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APPENDIX 1

Speech therapy recommendations for the mothers of children with cardiac disease

General Instructions: Read the text with the mother, ensuring comprehension. The text consists of four recommendations, and explanations, and a normal development reference table.23-25 Mothers must be warned regarding the proper use of these references, taking into consideration the possibility of variation based on the needs of each child.

Name:
Age:
Clinical picture:
Treatment stage:

Recommendation number 1: Assume that the child will develop normally.

Explanation: A well-stimulated child will have a normal and healthy development. There is no one better than the mother to perform stimulation. However, the mother must maintain her role as a mother and not assume the role of a "specialist," e.g., a teacher, doctor, physical therapist, or speech therapist. A child needs a mother the most.

To show affection for the child and desire that he/she becomes completely normal is an indispensable step for a normal adulthood. This affection and desire provides for adequate growth. However, it is necessary to know how to behave towards the child during feeding, cleaning, caressing, playing, and cuddling. If all this is done with tenderness

and care and assuming that the child is normal and healthy, there is a great possibility that all will turn out well. The child's capabilities and needs, as well as the medical recommendations must, of course be considered.

The child may face many problems as a result of the heart disease, and the mother may be very tired from the series of events surrounding the disease, surgeries, and treatments. Nevertheless, it is important to remain optimistic, as with time one learns to deal with these difficulties. This cannot be taught; each mother will find the best solution by herself.

The importance of speaking honestly with the child about things that concern him/her, regardless of the difficulty, is well established. Talking to children about their abilities and difficulties, as well as their pains, discomforts or pleasures, and wellbeing, is a prerequisite for successful development.

The mother of a child with problems may assume that this communication will be difficult, owing to the child's limitations or age. However, we must not forget that human beings display an extraordinary capacity of overcoming almost all deprivations, provided someone talks to them. That means if someone talks to the child and the child talks back, giving meaning to all that is happening to him/her, the child will most probably recover from the disease.

Recommendation number 2: Mealtime is special: prepare the food and prepare yourself to offer the food.

Explanation: Throughout the first year of life, the baby's food changes considerably: he/she stops ingesting only liquids, breast milk, or formula, and starts eating foods with pasty a consistency, such as soups, purees, gelatins, and yogurts, and finally solid adult foods. These changes are important for various reasons: 1) they help with dentition and toning of the entire mouth, preventing the child from drooling and choking, 2) they support bodily posture, as the child progresses from a prone position for breastfeeding to an upright sitting position for eating at a table, 3) they provide motor development as the child learns how to use cutlery, requiring fine motor skills that are also used for holding a pencil when learning to write, and 4) they help with social development; by spending time with the family at the dinner table, the child will learn to converse, exchange ideas, and have fun.

The change in food type does not rely solely on the child's maturation, but also on the mother's conduct at mealtime. The mother should take pleasure in feeding her child by establishing a peaceful daily routine (a time and a place that suits them both); planning and preparing the food; offering the food in a patient and playful way, guiding the child towards becoming increasingly independent; and working towards mealtime becoming a family event, where sharing and affectionate and social exchanges take place. Even during breastfeeding the mother should take pleasure in offering her milk and prepare herself to do it.

Gradually, the food provided to the child must become more varied and with different textures. This process must not be hurried, as the child takes longer to chew and swallow and gets distracted. If the food being offered is not breast milk or formula, the child should remain sitting in an upright position facing the mother and the food should be offered in small amounts following the child's pace. Let the child touch the food and chose what he/she prefer. Tastes, temperatures, and textures must be taught so that the child can distinguish between sweet and sour, hot and cold, and hard and soft foods. The child should be taught to hold the milk bottle, cup, and utensils. Most important, it is necessary to talk to the child at mealtime! Play and have fun with him/her! For this reason, it is best to prepare the meals in advance (if you do not cook, determine the menu), and to prepare yourself to offer the food: you need to have the time and the willingness.

Interestingly, taste (tasty/not tasty; sweet/salty) is learned. The daily food routine determines the development of the child's taste; it is not inherent. Therefore, the greater the variety of food types, the more the child's "taste" will develop. It is also noteworthy that only human beings prepare food and prepare themselves to eat it. For these reasons, what is called the "feeding scene" becomes important: in a group (family), around a meal previously prepared, and everyone sharing its consumption. Finally, unlike other animals, humans do not just eat when they are hungry. The will of eating comes from just sensing an appealing aroma, seeing appetizing food, or hearing a much-appreciated type of food mentioned. Lastly, humans feel hungry also from pleasurable memories and for

this reason mealtime must be harmonious, calm, fun, and full of conversation.

Typical development references:

0–3 months: milk (maternal milk and/or formula)

3–6 months: milk (maternal milk and/or formula) and sweet purees

6–7 months: savory purees and fruit juices

9–12 months: solid food introduction

12 months onwards: solid foods, avoiding excessively hard or dry foods

Until the end of the third year of age, the child's food is adjusted based on the types of foods eaten at family meals.

Observation: introduce cups/mugs, plates, and cutlery from the second year of age.

Recommendation number 3: Talk, sing, and tell stories to the child

Explanation: To stimulate the child to talk, he/she must be spoken to at all times and in all places: during bathing, meals, and play. It is important to sing, tell stories, even if the child will understand almost nothing. Create talking games and repeat them daily. Above all, one must speak to child imagining that the child "talks."

It is also very important to talk while looking at the baby, using a melodious voice; this guarantees the child's attention and surrounds him/her with affection. Gradually, this more infantile and melodious pattern must be modified. Other methods must be found to help the child to begin speaking. However, "talking like a baby" must be avoided; there is a difference between a slower, more melodious speech, and baby speech.

In the beginning, it is necessary to speak to the child and for the child: although the baby only cries and makes mouth "noises," one must act as if he/she was "speaking." Later on, the child starts repeating phrases and eventually full sentences: it is worthwhile to demonstrate joy and keep talking to the child as if it was not a repetition. On certain occasions, the child will make mistakes, but he/she should only be corrected afterwards. During this period, one must not comment on the mistakes, only present the correct way in the answers or commentaries. The mistakes must not be repeated. The child needs time to start the self-correction process. When it starts, you will find that the child's speech is in full development.

It is important to tell stories, report "cases," and remind the child of his/her own experiences. At first the adult will create the story alone, and later the child will begin participating as if both were having a conversation. After that the child may start telling small tales, little stories, even without the aid of an adult.

Typical development references:

Up to 6 months: the baby cries when in pain or hungry, wakes up with intense noises, is soothed by the mother's voice, mumbles, looks up when called, starts saying duplicated syllables ("mama/dada").

Up to 12 months: the baby plays with others, repeats sounds/words produced by others, responds to daily commands ("send kiss/say bye-bye").

Up to 24 months: the toddler uses speech to express his/her needs, to ask, to inform, to get attention; he/she uses isolated words and starts saying small sentences, keeps a dialogue with others, responds to commands of two or more actions ("pick up the key and put it in the drawer"), significantly increases his/her vocabulary, sings, retells small stories or favorite passages from children's stories.

Recommendation number 4: Play with the child at all opportunities

Clarification: Play time is the moment of excellence for language to emerge. All the symbolic operations of abstraction and generalization depend on constructions performed during play.

Typical development references:

0–6 months: The baby looks at an object and explores it in different ways (licking, shaking).

6–12 months: The baby begins to play with another person (hiding/peekaboo).

12–18 months: The exploratory play becomes varied (assemble/disassemble).

18–24 months: The toddler starts reproducing daily life activities during play using toys and discovers the social function of objects (the make-believe initiates).

24–36 months: The toddler starts to play in pairs and in groups.

Esclarecimento: A brincadeira é lugar por excelência da emergência da linguagem. Todas as operações simbólicas de abstração e generalização

dependem das construções feitas no brincar.

Referências sobre o desenvolvimento típico

0-6m: a criança olha para o objeto e o explora de diferentes formas (lambe, sacode)

6-12m: começam as brincadeiras a dois (esconde-esconde)

12-18m: a brincadeira exploratória é variada (montar/desmontar)

18-24m: começam a reproduzir o cotidiano por meio de brinquedos, descobre a função social dos objetos (começa o faz-de-conta)

24-36m: começam as brincadeiras em pares e em grupo