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Emotional aspects of parents of children with dysphagia

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ABSTRACT

Dysphagia is a common swallowing disorder in the pediatric population, which may influence the quality of life and well-being of the family. The literature points to stress, guilt, and social isolation of family members. However, the management of psychosocial aspects involved in the treatment of pediatric dysphagia is rarely discussed. This study aimed to carry out an integrative review of the literature regarding the emotional aspects of parents of children with dysphagia. Therefore a search in the databases SciELO and PubMed was made, from January 2013 to June 2020, using the descriptors in Health Sciences (DeCs): "deglutition disorders" and "child". The search was performed with English and Portuguese language limiters using associated descriptors. The selection of the studies was performed by reading the title, abstract and, if necessary, full text, applying the inclusion and exclusion criteria. There were 2,169 publications, and 8 met the inclusion criteria. The included studies were examined according to the author, type of study, goals, emotional aspects involved in the treatment of swallowing disorders, and conclusions. The analysis was performed according to the presence of certain variables of the emotional aspects presented in the face of swallowing disorders, namely, parental stress, negative impact on parent/child interaction, guilt and frustration, and social isolation. The literature points out that pediatric dysphagia causes an emotional impact on the parents; indicating that it is necessary to offer emotional support and to adapt the clinical management to the different demands present in the clinic.

Keywords: deglutition disorders; child; enteral nutrition; parent-child relations.

INTRODUCTION

Dysphagia is a swallowing disorder that may start in childhood due to prematurity, neurological or mechanical problems, gastroesophageal reflux, or heart disease. The risks in dysphagic cases are laryngeal penetration or tracheal aspiration of saliva, bolus, and/or gastric content with a risk of acute and chronic infection of the airways[1-5].

In recent years, there has been an increase in the incidence of dysphagia cases in the pediatric population due to the increased life expectancy of premature newborns and children with complex clinical conditions, with pneumonia being the most recurrent cause in children[1,2,4,6,7]. The prevalence of dysphagia in patients admitted to neonatal intensive care units indicated in some studies is 60%, while the incidence in children with typical development is 25 to 40% and 30 to 80% in children with developmental disorders[5,8].

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In cases of dysphagia, the need for adaptation of oral feeding and/or the use of an exclusive alternative route for nutrition, hydration, and administration of medications must be evaluated[4,9,10]. The therapy in these cases must seek safe swallowing and airway protection, to prevent possible clinical complications, and ensure an adequate nutritional status[11].

Moreover, it is not only physical clinical complications that we find in these cases. Studies show that childhood dysphagia can influence the quality of life and well-being of the family, including feelings such as stress, guilt, and social isolation associated, directly or indirectly, with feeding times[12,13].

In a qualitative meta-analysis assessing the impact of tube feeding on mothers' emotional state and identity, Wilken[14] states that there is psychological significance in feeding one's child that transcends the nutritional aspect, based on data suggesting that feeding an infant orally is not only an important aspect of motherhood but also a key element in the development of maternal identity. Non oral feeding often results in psychological stress for the mother.

In a prospective cohort study, which aimed to study the influences of infant and maternal feeding behavior on weight gain and growing deficit in the first year of life, the authors found that the extent to which caregivers respond to food refusal was an inversely significant predictor of weight gain, i.e., the more they responded to refusal, the less weight gain[15].

In addition, other studies present some notes associating the negative impact on the quality of life of caregivers with transgressions of the proposed treatment[16-18], which can lead to bronchoaspiration and consequently clinical complications, such as fever, pneumonia, or respiratory failure, thus impairing the treatment and rehabilitation process[19]. Despite this complexity of aspects, little is discussed about the management of the emotional issues involved in changes in the feeding routine or even in the interruption of oral feeding in infants and children.

Aware of the impact that the emotional aspects of parents or caregivers can have on the treatment of childhood dysphagia, the present study aims to conduct an integrative literature review in search of studies that address the emotional aspects of parents of children with dysphagia.

METHODS

Selection Criteria

The keywords selected were "swallowing disorders" and "child".

The databases used for the literature search were Scientific Electronic Library Online (SciELO) and the US National Library of Medicine National Institutes of Health (PubMed). The search was performed by associated descriptors.

The inclusion criteria were: articles in Portuguese or English, published from January 2013 to June 2020.

Articles in other languages and literature reviews, conducted with adult populations, animals, and those without abstracts or full texts were excluded.

Two independent researchers selected relevant articles based on the information obtained in the titles and abstracts according to the inclusion criteria mentioned above and searched for possible mention of parental emotional aspects. Duplicate publications were excluded. Then the full texts were consulted.

It is worth noting that the review included studies whose population was parents and other studies in which the population was children. However, in the latter, the procedures used involved questionnaires for parents with information about emotional aspects and for this reason, they were also considered in the analysis. Longitudinal, cross-sectional, qualitative, and clinical case studies were included.

Data related to the following emotional aspects present in parental discourse were obtained in the review of the full articles: parental stress, negative impact on parent/child interaction, guilt/frustration, and social isolation. These variables were established a posteriori, organized by frequency of appearance, and then analyzed based on the literature.

To define these variables of analysis, after reading the full texts, all terms related to emotional aspects were listed in an Excel spreadsheet.

RESULTS

The PRISMA diagram[20] (Figure 1) indicates the number of articles identified, excluded, and analyzed. In summary, the literature review found 2169 articles, of which 1478 were excluded because they did not fit the period established for this research, 34 were publications in other languages, 12 were publications not available in full, 1 was duplicated, 47 were with adult populations, 4 involved animal studies, 578 did not address emotional aspects of parents of children with dysphagia, and 7 were literature review studies. The eight studies included in this review are detailed in Table 1.

The variables about the emotional aspects of parents found in these studies were parental stress, negative impact on parent/child interaction, guilt and frustration, and social isolation.

The most incident variable was parental stress (n=6), followed by the negative impact on caregiver-child interaction (n=3) and the presence of guilt and frustration over the inability to feed the child (n=3). Some studies also pointed out that childhood dysphagia can also cause social isolation (n=2).

Parental stress was addressed in studies with patients with gastrostomy, cerebral palsy, premature babies, or patients who ingested alkaline battery and was related to prolonged mealtime, the volume of diet ingested orally, concern about nutrition and growth, and feeling of overload related to childcare. In addition,

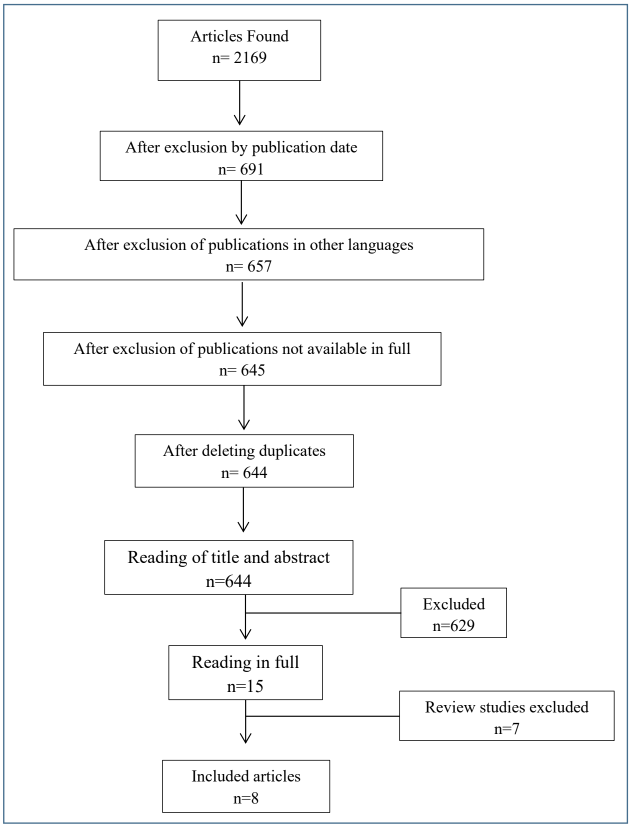

Figure 1: PRISMA Flow Diagram

these moments of stress linked, directly or indirectly, to the feeding scene were also related to a negative impact on the interaction between caregiver and child. The experience of caring for a dysphagic child was related to a range of feelings including sadness, guilt, frustration, and difficulty in participating in social situations involving food.

Some maternal reports found in the studies analyzed indicate that the overload of care, in addition to the need to reorganize the routine, usually leads to the abandonment of extradomiciliary work, which can affect the financial condition of the family and reduce leisure opportunities, resulting in social isolation. Moreover, another factor that can cause the isolation of this family at home is facing social situations, dealing with the curiosity and prejudice of other people regarding tube feeding of the child, for example[21].

Some studies have also indicated the presence of guilt and frustration over the inability to feed the child and the child's difficulty in making progress in this regard[22-24].

DISCUSSION

Emotional aspects of parents of children with dysphagia are still little explored in the literature. Although they are mentioned in some studies, the impact of such aspects on treatment, their management, and how much they can compromise therapeutic success remain little explored. This review points out that cases of childhood dysphagia can have an emotional impact on parents, and may influence the well-being, quality of life, and even the treatment of these children. The data highlights the main problems experienced by parents and/or caregivers and points out areas where family support can be improved.

Parental stress during meals emerged as a strong and recurrent theme that aligns with what we found in the literature about caregivers' reports about the time spent on oral meals being prolonged, besides feeling difficulty in the administration of liquids, which makes these moments even more stressful[25,26]. Another aspect raised that causes stress in parents/caregivers is the cycle of symptoms and clinical complications caused by dysphagia and, at the same time, the desire that their children have an expected development for their age group and eat normally[1]. The literature also shows that children with cerebral palsy and dysphagia, for example, often need more time to achieve oral feeding; however, this prolonged time may cause fatigue and reduced attention span, further extending the meal and increasing the level of stress felt by the family and child[26,27]. A review study[28] also pointed out that many caregivers, concerned with nutrition and growth, try to increase the volume of diet taken orally by adding more meals throughout the day. This initiative, however, increases the stress of both caregivers and children[28], generating a negative impact on the interaction between caregiver and child as pointed out in some of the studies reviewed[21,29-32].

Regarding the data found in some studies that indicate the presence of parental guilt and frustration for the difficulty of feeding the child and the absence of positive responses from the child in this aspect, it is verified that they are in line with what we see in the literature that shows that patients commonly undergo nutritional monitoring, controlling growth and weight gain and that in these cases, the growth of the child with dysphagia can be seen by parents as a reflection of their (in)ability to nourish[18,33]. Listening to parental narratives and the meanings they attribute to feeding can provide important information on how best to offer support in these cases[25].

The social isolation resulting from the high demands of care experienced by parents of dysphagic children[21,24] was also verified in a review of the literature on the topic[25] which suggests that structured support should be incorporated into the care of dysphagic patients.

The presentation of these emotional aspects through the perception of parents of children with swallowing disorders reinforces the importance of such data for speech pathologists to reflect on how the guidance to families has been performed and how it is possible to maximize the understanding and adherence of parents to the proposed treatment.

The studies that address this theme are still scarce, mostly qualitative studies, with small samples and reviews of children with

Table 1: Details of the studies.

Author/ Year	Study design	Population	Procedure(s) performed	Results
Avitsland et al. 2013[29]	Longitudinal	58 parents of children using GTM. Mean age of children: 1.7 years.	Semi-structured interview and application of a questionnaire at 3 moments: 0 to 3 days before the insertion of the GTM, 6 months, and 18 months after the insertion of the GTM.	Feeding is unpleasant for children and their parents. After GTM, there are reports of reduced stress, increased satisfaction of child and parent during meals, and improved communication between parent and child during meals. Increased oral intake and reduced vomiting. Growth improved in about half of the children.
Smith et al. 2014[22]	Exploratory cross-sectional	14 parents of dysphagic children using thickener in liquid foods, aged 2 to 12 years.	Semi-structured interview	Parents reported that they did not receive information about how and why to use thickeners in foods. They reported frustration, depression, and unhappiness. The indication to use thickener did not take into consideration the emotional impact it might have on the family. However, there are positive reports, such as a reduction in episodes of pneumonia. Detailed written information about the use of thickener is suggested
Cowpe et al. 2014[23]	Transversal	14 parents of dysphagic children aged 2 to 11 years.	An interview using a semi-structured questionnaire	Parents reported high levels of anxiety, frustration, distress, and feelings of not being heard. They described associated feelings of guilt and helplessness over their child's failure to thrive, and frustration in their search for answers.
Bilgin e Wolke 2017[30]	Longitudinal	73 extreme preterm and low birth weight babies and their parents + 105 babies born at term and their parents.	Observation of the mother-infant binomial to evaluate maternal sensitivity in 3 moments: in the first 10 days of life, at 6 and 18 months of corrected age.	TDs are frequent in preterm and low birth weight newborns and subsequently are associated with lower maternal sensitivity. In term newborns, lower maternal sensitivity was predicted by TD and associated with more TD over time. Dysphagia is stressful for the family and affects mother/baby interaction.
Benfer et al. 2017[27]	Population-based longitudinal	179 children with cerebral palsy aged 18 to 60 months and their parents.	Evaluation of swallowing and gross motor function, and anthropometric measurement of the children. Application of a questionnaire with the parents or an interview when necessary to clarify doubts. After the first evaluation, the parents recorded the child's feeding diary for 1 month.	Parents are stressed during meals, concerns about growth because they think the child is not eating enough, and respiratory conditions.
Follent et al. 2017[31]	Case Study	2 children in ongoing treatment for injury after ingestion of alkaline battery. Age of the children: 20 months and 22 months.	Evaluation of swallowing, and application of questionnaires with the parents.	Recovery from dysphagia after alkaline ingestion is lengthy and complex. Dysphagia delayed oral motor skills, and difficult mealtime behaviors may persist. Meals become stressful times for parents.
Follent et al. 2017[24]	Case Study	5 parents of children with dysphagia due to chemical or battery ingestion injury.	A questionnaire was applied to the parents and a semi-structured interview was conducted, on average, 4 years after the injury.	The absence of support for families in managing dysphagia can reduce the caregiver's quality of life and well-being. Stress, guilt, and social isolation may result. Family-centered care models are needed to support family members in caregiving.
Banhara et al. 2020[21]	Qualitative	7 mothers of infants older than 30 days and using a feeding tube.	Unstructured interview of approximately 40 minutes.	High level of stress and feeling of overload related to the burden imposed by the care of the child being fed through a tube, plus care for the house, other children, spouse, etc. In addition to restricting social interaction, prioritizing child care. The high burden of caregivers is associated with symptoms of stress, anxiety and depression in different degrees. Health professionals should include monitoring of the physical and mental well-being of caregivers in the process of caring.

chronic non-progressive encephalopathy, this being a limitation of this review. It is worth pointing out the importance of developing new studies pointing out the possible implications of these emotional aspects in the treatment of different dysphagic conditions, generating scientific evidence on the subject.

Conclusion

The literature analyzed points out that childhood dysphagia causes an emotional impact on parents, mainly stress during meals, negatively impacting the interaction with the child, social isolation, and feeling of guilt for the child's inability to feed orally. In these cases, it is necessary to offer emotional support and adapt the management to the different demands that present themselves in the clinic. Therefore, it is important to give voice to the family and welcome their anguish and concerns, aiming to offer comprehensive health care, focused on the needs of the child and his family.

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