Difficulties faced by parents of children with gastroesophageal reflux disease

Dificuldades enfrentadas pelos pais de crianças com doença do refluxo gastroesofágico

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Abstract

Objective: Identifying the difficulties faced by parents of children with gastroesophageal reflux disease.
Methods: Qualitative study carried out with 16 parents of children with gastroesophageal reflux disease. A guiding question was used and the interviews were recorded and transcribed.
Results: Eight categories related to the difficulties faced by parents emerged, as follows: frequent vomiting, pneumonia, cost of treatment, impaired social interaction, weight loss and disturbed sleep pattern, causing difficulty in adhering to treatment with insufficient guidance.
Conclusion: The difficulties faced by parents of children with gastroesophageal reflux were represented by categories that can serve as indicators for the quality of provided care.

Resumo

Objetivo: Identificar as dificuldades enfrentadas pelos pais de crianças com doença do refluxo gastroesofágico.
Métodos: Pesquisa qualitativa realizada com 16 familiares de crianças com doença do refluxo gastroesofágico. Foi utilizada uma questão norteadora, as entrevistas foram gravadas e transcritas. Utilizou-se a técnica de análise de conteúdo.
Resultados: Emergiram oito categorias relacionadas às dificuldades enfrentadas pelos pais: vômitos frequentes, pneumonia, custo com tratamento, convívio social prejudicado, perda de peso, padrão de sono prejudicado, gerando dificuldade na adesão ao tratamento com orientações insuficientes.
Conclusão: As dificuldades enfrentadas pelos pais de crianças com refluxo gastroesofágico foram representadas por categorias que podem servir de indicadores para a qualidade do cuidado prestado.

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Introduction

The gastroesophageal reflux (GER) is characterized by the involuntary passage of gastric contents into the esophagus and may occur several times during the day in healthy children and adults, being classified as physiological or pathological. It reaches 7-8% of children and is present in about 50% of children in the first four months of life.[1]

The reflux is characterized as physiological when presented in the first months of life. The postprandial regurgitation arises between birth and the first six months of life, often with spontaneous resolution until the first year of the child.[2-4] In this context, conservative strategies that do not require medication therapy are indicated, since they have several benefits, low cost and no side effects.[3,5-7]

In addition to vomiting and regurgitation, other signs and symptoms are present in the gastroesophageal reflux disease, impairing the clinical status of patients. This clinical impairment may be primary, with some dysfunction in the esophageal-gastric junction, or secondary, when it results from food allergy or intestinal obstruction.[2,8,9]

The difficulty of professionals is noticeable in the daily practice of care to children with gastroesophageal reflux, in the management of these patients. Some measures are important to minimize or avoid the onset of reflux.[2,3,10] In this aspect, nurses are indispensable caregivers, and the adherence of parents to treatment is critical in order to reach a successful outcome of the nursing guidelines.

The relevance of the study for nursing is linked to ensuring quality of treatment and effectiveness in child care. It is believed that nurses can make a difference because of the specificity of the profession, when leaving the reductionist approach focused on the illness for the biopsychosocial approach, by ensuring relevant guidance and unlimited support to parents or guardians of children with this condition.

The objectives of this study were to identify the difficulties faced by parents of children with gastroesophageal reflux and develop an educational brochure with relevant guidelines to the topic.

Methods

It is a descriptive study with qualitative analysis, focused on the subjects' expression of subjectivity. In qualitative research, results are developed in a natural situation with an open and flexible plan and addressing the reality in a complex and contextualized way.[11,12]

This research was carried out at a large institution in the city of Goiânia, Goiás, west central region of Brazil. It attends approximately twenty parents of children with gastroesophageal reflux per month. The parents or guardians of children served in the outpatient clinic of Gastroenterology participated in the study. In total, were included 16 parents of children aged between zero and five years who met the following inclusion criteria: age over 18 years and being a companion at the time of consultation.

In order to achieve the proposed objectives, the adopted procedure for data collection were interviews based on the following guiding question: What are the difficulties you face when caring for a child with gastroesophageal reflux? For data analysis, the technique of content analysis was used.[13]

Parents were interviewed and the statements were filed in a digital recorder, with subsequent full transcript.

The development of study followed national and international standards of ethics in research involving human beings.

Results

Eight categories related to the difficulties faced by parents of children with gastroesophageal reflux were identified: Frequent vomiting, pneumonia, cost of treatment, impaired social interaction, weight loss, impaired sleep pattern, difficulty in treatment adherence and insufficient guidance.

Discussion

Limitations of this study are related to qualitative design that allows the identification of the meanings of phenomena and qualitative characteristics that make the object of study, without establishing relations of cause and effect.

The categories related to the difficulties faced by parents of children with gastroesophageal reflux were: frequent vomiting, pneumonia, cost of treatment, impaired social interaction, weight loss, impaired sleep patterns, difficulty in treatment adherence and insufficient guidance.

The presence of vomiting is closely related to the child's position, especially in the postprandial period.[9,14] Regarding vomiting, 75% of parents reported difficulty with its management, and in relation to positioning approximately 20% had problems.

Although nonspecific, vomiting and regurgitation are the most characteristic symptoms of gastroesophageal reflux.[2,3,15] The high number of children with these episodes in the first two quarters of life may be a result of early weaning and the introduction of complementary feeding, since the offered amount is imposed by the caregiver and not necessarily controlled by the child.[5,14]

The small gap between meals, the positioning and handling of the child in the postprandial period may contribute to the presence of gastroesophageal reflux (GER), and in children who are more sensitive to the presence of gastric contents into the esophagus, it can trigger symptoms similar to esophagitis, justifying the suspicion diagnosis of gastroesophageal reflux.[5,9,16]

According to testimonies, vomiting and/or regurgitation are present in the lives of these children, causing anxiety in parents. This fact requires further approximation of nurses, in an attempt to minimize this situation with care and the guidance appropriated to the level of understanding of the family.

Also in relation to vomiting and regurgitation, pneumonia is the pathology that became common in the lives of these children. All respondents reported that their children had pneumonia at least once during treatment.

Gastroesophageal reflux can cause respiratory disease by two mechanisms: vasovagal response and tracheal aspiration of gastric contents.[3,10,17] Tracheal aspiration is considered the main risk factor for the occurrence of recurrent respiratory infections, asthma attacks and worsening of patients with chronic lung disease.[3]

The aspiration of gastric contents may occur especially at night, when the child is lying and has persistent cough and difficulty breathing. There should also be a suspect of reflux when the patient is awakened by asthma-like attacks, bronchopneumonic processes or sinusitis without evident cause.[2]

Guidance provided by the nurse, such as positioning the child in the elevated left lateral decubitus, not lying down immediately after meals and not eating fatty or greasy foods can bring benefits during treatment and avoid various complications such as pneumonia, sinusitis and frequent hospitalizations, relieving the anguish of the family.[8]

The emotional distress of parents of children with GER is often related to financial difficulties. Faced with the impossibility of completely funding the treatment of the disease, the family feel helpless and anxious, since they also need to meet domestic and personal needs, which remain in the background. Many times, the high cost of the prescribed milk, the diet with specific foods, and the costs with medications hamper adherence to treatment.[14]

Working in the health area requires the training of professionals, who need technical and scientific expertise, in addition to sensitiveness to the reality of the population they work with. Therefore, the financial difficulties of the families should be taken into account in the set of actions developed to solve the problem.

Children with gastroesophageal reflux have some problems related to feeding that reflect in their social lives.[2,3,5,13] In this study, it was possible to observe the difficulties of families due to depriving their children of various foods common to healthy children. Such as occurred with exposure to certain situations in commemorative celebrations, visits to relatives and friends, when children manifested willingness to eat not rec-

ommended foods. This social deprivation negatively impacts on the entire family context because the social isolation of the child, therefore, results in the isolation of parents.[5,18]

Regurgitation, vomiting, functional dysphagia, acid or bitter taste in the mouth, postprandial discomfort, nausea and abdominal pain are symptoms that usually affect children with gastroesophageal reflux disease, leading to significant weight loss.[2,3,18,19] Many parents reduce the supply of food in face of the discomfort felt by their children and have difficulty in administering sufficient quantities of food in a timely manner.[5] The resultant digestive symptoms, which often contribute to functional impairment, make children inappetent.

Children with gastroesophageal reflux disease may also develop oral hypersensitivity, hindering the acceptance of foods of different consistencies and textures. In this sense, the nurse has an important role with food guidance, such as not offering acid, fatty or forbidden foods like chocolate and soda, as well as maintaining a fractioned and preferably pasty diet.[3,16,20]

Other features presented by children with gastroesophageal reflux are irritability, excessive crying, sleep disorders, hiccups, restlessness and refusal to eat. These symptoms are routine reasons for consultations, especially for infants younger than three months. At this age, 50% of infants have gastroesophageal reflux, and therefore the coexistence of these findings itself, does not constitute a causal relationship.[3,5,16]

Experiencing gastroesophageal reflux on a daily basis can mean physical and emotional distress of both the child, as the caregiver. The discomfort caused by the symptoms of the disease makes children angry and tearful, requiring extreme dedication and attention of parents to ensure that more severe complications do not occur, such as aspiration followed by respiratory arrest. In this sense, nurses need to be alert to provide adequate information about sleep management and emergency training in case a more serious event occurs.[3,6,21]

Although gastroesophageal reflux in children is quite common, this study found there are still great difficulties in full adherence to the treatment and the provided guidance. This is because adherence is subject to many factors such as demographic, social and economic conditions, the nature of the disease, the treatment characteristics, as well as the relationship of the patient with health professionals.[22]

Thus, the first step of treatment is the proper parental guidance about what is the gastroesophageal reflux disease, with emphasis on symptoms arising from inadequate diets and possible complications resulting from the non-use of prescribed medications. Guidelines should be adapted to the socioeconomic profile of those involved, extending to all family members, in order to involve them in the commitment to properly caring for the child.[3]

The diagnosis of pediatric gastroesophageal reflux disease is made by clinical history and tests (endoscopy, radiological contrast examination of the esophagus, scintigraphy, manometry, 24-hour pH monitoring, therapeutic test).

The treatment is clinical, with behavioral and pharmacological measures and, in the case of complications, the surgical endoscopic treatment may be necessary.

The nursing care should be family-centered, in close communication between nurses and parents, keeping them informed throughout the therapeutic process about possible complications, and especially the ways to minimize and correct this situation.

Conclusion

The difficulties faced by parents of children with gastroesophageal reflux disease were represented by the following categories: frequent vomiting, pneumonia, cost of treatment, impaired social interaction, weight loss, impaired sleep patterns, difficulty in treatment adherence and insufficient guidance.

Collaborations

Oliveira GB and Gualberto SM contributed to the project design, execution of the research and writing of the article. Brasil VV and Silva AMTC collaborated with the relevant critical revision of the intellectual content. Cordeiro JABL contributed to the project design and execution

of research, writing the article and final approval of the version to be published.

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