Repercussions of cow's milk allergy from the perspective of mothers

Repercussões da alergia ao leite de vaca sob a ótica materna

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- Pamela dos Reis¹
- Sonia Silva Marcon¹
- Vanessa Carla Batista¹
- Verônica Francisqueti Marquete¹
- Evelin Matilde Arcai Nass¹
- Patrícia Chatalov Ferreira¹
- Sueli Mutsumi Tsukuda Ichisato¹

¹Universidade Estadual de Maringá. Maringá, PR, Brazil.

Corresponding author:

Pamela dos Reis Universidade Estadual de Maringá. Av. Colombo, 5.920, Jd. Universitário. CEP: 87020-900. Maringá, PR, Brazil. E-mail: pamdosreis@gmail.com

ABSTRACT

Objective: understanding the repercussions of cow's milk allergy from the perspective of mothers. Methods: qualitative study, carried out with nine mothers who were found in Facebook groups. Data was collected through semi-structured interviews and submitted to content analysis. Results: three categories emerged: living with the unpreparedness of health services and professionals to diagnose and treat allergies to cow's milk protein; social isolation: the result of fear and misunderstanding; and the mother as the central figure of care. Conclusion: the rigorous alimentary restriction that results from allergies to the protein in cow's milk significantly reverberates in the lives of children and families, especially mothers, leading to the social isolation of the family and to insecurity in the use of health and education services, due to the lack of knowledge and preparation of the professionals.

Descriptors: Milk Hypersensitivity; Maternal and Child Health; Social Support; Breast Feeding; Diet.

RESUMO

Objetivo: compreender as repercussões da alergia à proteína do leite de vaca, sob a ótica materna. Métodos: estudo qualitativo, realizado com nove mães, as quais foram localizadas em grupos do Facebook. Dados coletados por meio de entrevistas semiestruturadas e submetidos à análise de conteúdo. Resultados: emergiram três categorias: Convivendo com o despreparo dos profissionais e serviços para diagnóstico e tratamento da alergia à proteína ao leite de vaca; Afastamento social: resultado do medo e da incompreensão; e A mãe no centro do cuidado. Conclusão: a rigorosa restrição alimentar, decorrente da alergia à proteína do leite de vaca, repercute significativamente na vida de crianças e famílias, em especial das mães, desencadeando isolamento social da família e insegurança na utilização de serviços de saúde e educação, devido ao desconhecimento e despreparo de profissionais.

Descritores: Hipersensibilidade a Leite; Saúde Materno-Infantil; Apoio Social; Aleitamento Materno; Dieta.

Introduction

In the last decades, there has been an increasing number of allergic reactions to foods. It is possible to state that food allergy is a growing contemporary nutritional problem⁽¹⁾. This type of allergy is a specific and repeatable immunologic response, which results from the exposure to a specific food antigen, generally a protein, which generates a hypersensitive immune response⁽²⁾.

Any food can generate allergies, but among newborns and small children, cow's milk is the main responsible. A study carried out in public services of nutritional care, in 34 Brazilian cities, found a prevalence of 0.4% of Cow's Milk Protein Allergy (CMPA)⁽³⁾. However, estimating the prevalence of this type of allergy is difficult due to its natural history, since the there is a relatively high rate of patients who overcome the disease after early childhood. When the milk is boiled, its potential to trigger allergic reactions also diminishes, since this process leads to changes in some of its proteins. Furthermore, reactions to cow's milk that are unrelated to the immune system, such as lactose intolerance, may lead to an overestimation of this prevalence in self-report studies⁽⁴⁾.

CMPA may trigger many symptoms, depending on the immunologic mechanism involved. Most reactions take place immediately after ingestion, due to the excessive production of immunoglobulin E (IgE) for a certain type of food. These reactions may affect skin and/or mucous membranes, airways, and gastrointestinal and cardiovascular systems, either in isolation or not. In other cases, the allergy may manifest later, mediated by cells (lymphocytes and eosinophils) that mostly affect the skin and the digestive tract^(2,5). In severe cases, small quantities of milk may lead to lethal reactions within 30 minutes to 2 hours⁽²⁾. Some children even presented reactions through inhaling the allergen or having it touch their skin^(2,5).

Allergic manifestations to cow's milk protein start in the first months or days of life and are mostly temporary, hardly ever lasting beyond the second year of life⁽⁵⁾. Treatment is centered around a diet that entirely eschews cow's milk and its by-products, as well as foods with traces of it, with the addition of oral immunotherapy in some cases⁽⁶⁾. Accidental ingestion may take place due to contamination, during the industrial processing of foods, or due to the consumption of products containing cow's milk who name the product it differently, making its identification more difficult^(2,5).

Regardless of the severity of the reaction itself, this condition requires greater care with health, especially with the feeding of the child. It requires more dedication and attention from mothers, who in most cases are those responsible for the children⁽⁷⁻⁸⁾.

In addition to this context, it should also be stated that the personal experiences of the first author of this paper were the reason that reverberated and triggered the interest in carrying out this study, since she had to confront the reality of being the mother of a child with CMPA, dealing with the lack of knowledge of the general population and of the health professionals themselves, which led to insecurity and to hours of research for information.

Therefore, aiming to produce a study that could portrait the situation from the perspective of mothers, thus giving support to the management of nursing in the attention to children with CMPA and their families, the following question emerged: what implications does cow's milk protein allergy bring to the lives of children affected and their families, especially considering their mothers, who are their main caretakers? To answer it, the objective of the study was defined: understanding the repercussions of cow's milk protein allergy, from the perspective of mothers.

Methods

This is a qualitative study, carried out in a medium-sized city in the South of Brazil, with mothers who participate in on-line Facebook groups about CMPA. The groups were prospected by one of the researchers, who searched or mothers who publicly stated that they lived in the city on their Facebook profiles.

Later, through private messages in the social network itself, she invited the mothers that were found to participate in the study and scheduled the interviews.

Inclusion criteria were being an 18-year-old or older mother, having children with CMPA, and living in the city where the study took place. All 19 mothers found were invited to participate. The researchers did not know any of these mothers. However, among the 19, four did not see the message, one did see it, but did not respond, three reported that their children were actually lactose intolerance, and two had moved from the city. As a result, the number of participants was defined by exhaustion, since the study included all nine participants who answered to the messages and were in accordance to the criteria established. This number made it possible to approach the subject and identify common themes, which allowed the objective of the study to be reached.

Data were collected from January to March 2017, through semi-structured interviews carried out by the two first authors in the houses of the participants, except in one case, in which the participant preferred to be interviewed at work. A semi-structured script was used, addressing socioeconomic features of the participants (age, education level, and family income) and the following guiding questions: tell me about your experience as the mother of a child with cow's milk protein allergy. What has made this experience easier or more difficult? What helped you understand this condition? The interviews were recorded in audio, after the participant agreed, and lasted for a mean of 45 minutes. They were later transcribed in their entirety – if possible, in the same day they were carried out. The transcribed material was not given back to the participants for complementation or correction.

Data were submitted to content analysis, thematic modality, following the three stages proposed⁽⁹⁾. In the pre-analysis stage, a superficial reading of the material was carried out, and the corpus of the analysis was built. During material exploration, the criteria of exhaustion, representativity, homogeneity, and pertinence were used to identify the record units. Finally, in the result-treatment stage, statements were synthesized, and, through their understanding, the central meanings were identified, and the categories were conceptualized.

The theoretical framework adopted was the Family Systems Theory, an adaptation of the general systems theory that sees the family as a system in which the members are singular units with distinct behaviors, who complement each other and constantly interact, aiming to achieve a goal. Despite the interdependency that makes up this whole, if one is to understand it one must consider each of its parts, since the conduct and experience of each member of the family unit will influence and affect the entire system⁽¹⁰⁾. Therefore, the family system is constantly built and rebuilt, always aiming at good coexistence, and to remain balanced when facing destabilizing problems, such as situations in which one of them gets ill. When the Family Systems Theory is applied to nursing, the family can be observed as a unit of care, thus receiving a more humane, holistic, and resolutive healthcare⁽¹⁰⁾.

This project was approved by the Ethics Committee for Research with Human Beings of the participating institution (No.1.868.933/2016). Participants signed the Free and Informed Consent Form and, in order to guarantee their anonymity during the presentation of the results, the extracts of statements will be presented using the letter M (mother) followed by a number indicating the order in which the interviews were conducted.

Results

The age of participants varied from 26 to 49 years old. Two mothers had complete high school, while the others had higher education. Their family income varied from 3 to 15 minimum wages. The time breastfeeding varied from 5 to 26 months. Seven women breastfed their children for more than one year, and four of them were still doing so by the time the interview took place. One participant was monitoring her child's health through the Single Health System, while

the others were using their health insurance. Three categories emerged from data analysis: living with the unpreparedness of health services and professionals to diagnose and treat cow's milk protein allergies; social distancing: the result of fear and of being misunderstood; and the mother as the central figure of care.

Living with the unpreparedness of health services and professionals to diagnose and treat cow's milk protein allergies

The frequent dismissal of the information offered by mothers, associated to superficial guidance, lacking scientific evidences and support, often undermined the necessary establishment of a relationship of trust between health professionals and the mothers of the children with this allergy. She cried a lot, because she felt pain, she couldn't sleep, and the pediatricians thought that it was because it's my first child, that I was overreacting. I had to go to five pediatricians before finding a diagnostic (M9). With the exception of the allergist and the gastroenterologist, the approach of the other health professionals is always superficial, they know almost nothing about the subject and treat us as ignorant and exaggerated (M1).

The lack of knowledge of professionals regarding the condition was seen as aggravating by the mothers, who reported that mistaken treatments were indicated. A pediatrician said: "but mom, this is lactose-free, this milk you can use". They don't know the difference between the allergy to cow's milk protein and lactose intolerance. We have to go after it and believe our sixth sense (M3). Some professionals mistook the allergy for lactose intolerance. Until I found a doctor who actually knew about the subject, we went through several pediatricians (M6).

The use of medication and vaccines required doubled attention from the mothers, since these can contain traces of milk in their formulas, and still be prescribed/indicated for children. When you give them medicine, you have to be really careful, to see if there are no traces in the formula. We need to make the subject more widely known, explain the severity of ingesting it, in vaccination campaigns, make it clear that some vaccines have traces of milk (M3). Two months after taking the vaccines started presenting bloodlines in the feces. We suspected it could be allergy to the vaccine [milk components], and it was (M1).

Once diagnostic and treatment are established, another preoccupation surfaced: the lack of preparation of child education institutions, which motivated some mothers to de-

lay the ingress of their children in schools. I'm afraid, that's why I still didn't send to school (M2). The school knows about the allergies, know the restrictions, but they don't take it seriously, they are not prepared to do so (M1). At school, some professionals think I'm exaggerating (M8).

Therefore, the reports in this category showed that families experienced difficulties due to the lack of professionals in the fields of health and education who were prepared to offer the care needed by this group of kids.

Social distancing: the result of fear and of being misunderstood

The food allergy had a significant effect on family life, especially on the child and the mother, since it made it more difficult to live in society, generating restrictions that affected the relationship with friends and extended family. Additionally, the necessity of being careful to avoid the exposure of the child to the allergen, when coupled with the fear of possible allergic reactions, generated moments of preoccupation and even embarrassment to the mothers. You have to be careful with touches, kisses, feeding, label reading, cosmetics, anything that people from the family and anyone closer use, to make sure there is no milk or any of the proteins in the formulation (M1). I avoided taking him some places, so they wouldn't notice, so, in the end, no one would go to my house. Because it's annoying. I kept saying all the time to people: clean your hands, clean your mouth, you can't hold him (M7).

The care changed as the children grew. That is because, while babies, the mothers reported they had control over what was ingested and what other people offered to their children. However, when the children started eating by themselves, the desire and curiosity for other tastes may lead to more frequent episodes of exposure to the allergen and/or to the frustration of the child due to such a rigorous and broad eating restriction. To minimize this aspect, a greater social distancing is more likely to take place. Isolating a baby is easy, but they grow, the friends offer.. they start to want (M3). Parties are always a great challenge, because he gets sad when he notices he can't eat anything. Then there's that anguish, you feel like "putting them in a bubble" (M8). Another challenge was when he started to understand the parties. He saw people eating and he wanted it. Everywhere I had to distract him so he wouldn't see it and eat it. I always brought a soymilk chocolate bar for him, which was like a consolation prize (M7).

The difficulties in caring for children with this type of

allergy can notoriously affect the family core, meaning that leisure activities that are essential for social and family interaction, such as traveling or eating out, are limited. The worst is the social aspect, that anyone with food allergies suffer, because people get together to eat pizza and you can't go, we practically don't have any options to eat out (M9). These days I couldn't make food at home, so we went to a restaurant. Apart from rice and beans, there was nothing he could eat... all the others were made with cream, vegetables were made on butter, and they made the meat on the same hotplate where they make the cheese (M3).

According to mothers, the care for the child with this type of allergy is, frequently, seen by others as exaggerated. For many participants, the lack of understanding from relatives and friends regarding the severity of the allergy led to uncomfortable social relations. It isn't easy being the mother of an allergic baby in a world in which only those who experience an allergy understand the word. Many people think it's overreaction, many "I gave him a small piece" (M3). I have been called overprotective many times (M6). We are called exaggerated, they say that a kiss after eating some protein will mean nothing (M1). People think like: "wow, what a neurotic! It's not all that". Even my mother, my father, older people. They would say: "Wow! We can't even touch". It was easier to avoid [the family] in some situations (M7).

CMPA was found to lead to lives in which there is social misunderstanding about the condition and the care it requires, which contributes for the social isolation of the children and their caretakers and can affect the life of the family as a whole.

The mother as the central figure of care

It is natural for mothers to feel responsible for the care of their children. However, the intense preoccupation with the exposure of the children to cow's milk protein make it so mothers are the center figures of care. Many of them even reported avoiding foods they found pleasurable. An example is breastfeeding in cases in which the child is extremely sensitive to traces of cow's milk. Traces from the eating habits of the mother may be present in their own milk. In these cases, the nursing mother also needs to have a cow's-milk-free diet. As much as I wanted to breastfeed, I thought I was going to go crazy. I thought there was no life without the things I used to eat. At first, I got really bad. But, to care for her [daughter], I'll do anything (M2). The hardest moments are when I need to eat out, since there are few foods with no milk or traces of it (M4).

The difficulty in adhering to the diet, in most cases, resulted from the need to be extremely careful in the preparation of foods, due to the risk of crossed contamination, which is something most people are unaware of. It is a challenge to make people understand that you can't mix it, you can't use the same spoon to stir... That is why it's practically impossible to eat in a restaurant. Crossed contamination is what people have the hardest time understanding (M9). At first, it was pretty difficult to fine tune the elimination diet, I ended up consuming traces of milk and she had a reaction. I started eating only at home, I ate a lot of fruit and dove deep in vegetables. And, like that, I breastfed until she was two (M6).

Despite the restrictions, some mothers report feeling relief once they saw that, by taking care of their own diet, the signs and symptoms of the allergy diminished or even disappeared. As a result, caring for the children through breastfeeding, despite personal deprivation, was seen as a priority. I breastfed during the diagnoses, when I took it seriously and went into an elimination diet, her reactions stopped (M1). It was great to see that, with my diet, the symptoms stopped, and the baby was breastfeeding well, with no pain (M4).

On the other hand, despite recognizing the undeniable benefits of breastfeeding, some mothers could not continue doing it. That happened due to the fear that mothers had of prejudicing the health of their children, their difficulties in adapting to the elimination diet, or even due to the lack of guidance on this type of diet and their benefits. I couldn't cook the special diet for me, and my fear of eating something without knowing it had milk and that hurting him[son] made me decide to stop breastfeeding... The formula seemed to me the alternative with the least traces (M3). I started to feel sick with the diet, since I couldn't prepare many things to eat and I felt really weak. Then, I breastfed one more month and gradually introduced the special formula (M7).

They also started to experience a lack of incentive to breastfeed, even from health professionals, who questioned the validity of making an effort to do so. The first thing you hear from misinformed health professionals is that you have to stop breastfeeding because your milk makes them ill. That's a lie! What you eat may be bad for the child, but mother's milk isn't. Most mothers prefer to give them the formula. When the person insisted on making me stop breastfeeding, I said "will you buy the milk? Each can costs 200" and they got scared. The person didn't understand the problem and, especially, how important breastfeeding is (M2).

Another preoccupation and motive for care were industrialized foods, which can only be consumed by mothers who are breastfeeding or by the children after the labels have been carefully read, which required time and patience. *When* we went to the marked, we spent hours reading labels, there were many calls and e-mails to companies that did not correctly discriminate the ingredients in the labels of their products (M6).

Even when the allergen is not used as an ingredient in the food, there might be traces that result from the fact that the same machines are used to process or pack the products. The lack of records in the labels about the possibility of crossed contamination means that the analysis carried out by mothers is inefficient and can lead to fear and anguish. The companies that produce milk-free products should be more careful, so that their products really have no traces. Labels should be clearer, because oftentimes it says no milk, but there is a reaction, and then you call customer service and they inform you that they use the same machine used to make products with milk (M3). He drank plant milk and got diarrhea, hives, swelling, and when I investigated, I found that they packed it in a factory that packs cow milk. This could lead to an anaphylactic shock, you know?! (M2).

The mothers of children with this allergy experience many different feelings and difficulties, since this is, in most cases, an unknown condition. From the start of the symptoms until diagnostic, it was difficult. Seeing that the baby is feeling pain and not knowing how to help is really difficult (M4). Everything contributed for a lot of stress, I suffered a lot, taking her to physicians and doing exams. I got tired, it's not easy at all (M9).

However, once they found information on the disease, and especially once they saw a clinical improvement in their children, they felt motivated to continue caring for them. Patience was mentioned as an essential attribute to deal with this problem. Sometimes we get really discouraged, but you have to be patient. It's the main thing, because it goes away, or at least gets better (M7). When you are aware of what the allergy is, the change happens without suffering, because we want the cure. We learn to seek alternatives and to live through this problem as positively as possible (M3).

However, it is important to highlight that, if on one hand the lack of support and understanding makes treatment difficult, on the other, the support of fathers and of grandparents of the child are very positive. My mom, my dad, and my husband gave me a lot of support. My mom always went after everything, helping me a lot (M2). My family always gave me support, seeking milk-free alternatives for what I like to eat [mother with eating restrictions to keep breastfeeding] (M4).

The exchange of experiences with other mothers in the same situation was also found to be beneficial. According to the reports, in addition to exchanging information on the disease and on necessary care, the opportunity to express preoccupation, anguish, but also victories, contributed for the emotional health of these mothers. The experience exchange with other mothers helped me a lot. Talking, venting (M5). What helped me a lot is that, in my son's classroom, there are two mothers with allergic children. They gave me tips and showed me the ropes to deal with the situation (M2).

Additionally, participation in groups on the theme in the media and in social networks, such as Facebook® and WhatsApp, were pointed out by mothers as important sources of information. A friend who is also the mother of a child with allergy to cow's milk protein put me in support groups in social networks that made all the difference (M6). I receive a lot of help from the people at WhatsApp (M5). Social networks help finding people who are going through the same situation, and in these groups, we find emotional help, help to find our way (M9).

It can be concluded that having a child with CMPA brings suffering, requires much effort, patience, self-deprivation and care, and that, in a way, interferes in the lives of all members of the family, although the process is focused on the mother, who, often, experiences the situation alone.

Discussion

A limitation of this study was the fact it was developed with samples from mothers with high educational levels and access to private health care. It also had as limitations the low number of participants and the use of a qualitative approach, which involves the subjectivity of the investigator but does not allow results to be generalized, and the fact that the transcription of the materials recorded was not sent back to the participants, who were thus prevented from complementing, correcting, or even disagreeing with previous statements.

These issues, regardless, do not invalidate the results obtained. They do the opposite, reiterating the need for new researches aiming at, for example, investigate how mothers with low educational levels and socioeconomic conditions deal with CMPA. Furthermore, in later investigations, the use of a different methodological framework would be adequate, to explore other aspects of the phenomenon.

The results of this study can contribute for te-

aching, research, and to the assistance in the field of child and family health, as it shows the lack of knowledge of the professionals, the lacks in their conduct, and the difficulties faced by mothers/relatives of children with CMPA. To care for the needs of this public, it becomes necessary to raise the awareness of professionals and train them with regards to this reality.

The results showed that, although the food allergy directly affects only the immune system of the child, the presence of the allergy leads to changes in the lives of all members of the family unit – especially the mothers, who are the main caretakers. This can be understood according to the Family Systems Theory, according to which the family unit (the whole) is made up of its members (parts), who mutually interact to reach a common goal. The experience of each member is influenced by the whole family system, and, simultaneously, influences it. The same happens with all other sub-systems – relatives, friends, health professionals, etc.⁽¹⁰⁾.

The obstacles regarding the CMPA are experienced since diagnosis, since many professionals do not know the specificities of this disease. It stands out that only IgE-mediated allergies can be identified by lab exams, which excludes the cases of cell-mediated allergies. As a result, the most appropriate test is the oral food challenge test⁽¹¹⁾, based on the knowledge of the professional and on the reports of mothers. Therefore, the statements of some mothers was found to corroborate studies from the Brazilian Association of Allergies and Immunology, according to which health professionals from public and private networks must be trained to diagnose and treat this type of allergy⁽¹²⁾ and to be sensitive to the complaints of mothers. These complaints are what start the investigation process.

The Family Systems Theory raises the need for the health team to go beyond treating the disease itself and the individual it affects. That means that health care must involve the family system as a whole, while simultaneously offering specific care to each of its parts⁽¹⁰⁾. According to a study on the psychosocial and behavioral impact of food allergies in children, adoles-

cents, and their relatives, it should be considered that all those who are more frequently in touch, those who are closer to the child, require care, especially with regards to information. Nutritional education strategies should involve community, including school and friends, so that people who habitually interact with the child can understand the importance of surveillance and the potential need for emergency care, thus contributing for the child to have the possibility of living a normal social life⁽¹³⁾.

To this end, it should be considered that teachers and those responsible for schools for young children must have knowledge on CMPA and other food allergies, since it offers safety and calm to the parents, since the children spend long periods in these spaces⁽¹³⁾. Moreover, the unpreparedness of education establishments to care for children with special dietary needs was the reason for some children whose parents participated in this study to have the start of their school lives delayed.

The professionals who work in the school environment must prevent the child from ingesting or getting in touch with foods that contain cow's milk, which is the main type of food for many children in this age group. They also must deal with the possibility that the child will feel excluded, a possibility that worries mothers and is related to the emotional well-being of the child. A study carried out in New York, with 80 children with several different types of allergies and their families, showed that the group with food allergies presented a significantly higher score in the Multidimensional Anxiety Scale for Children, including higher scores in the rates of rejection to humiliation and social anxiety⁽¹⁴⁾.

People in the social circle of the family of the child with CMPA showed lack of support and understanding about the severity of the situation, which can make treatment even more difficult, in addition to leading to the social distancing and isolation of both the child and the family⁽¹³⁾. This is especially true when this condition is dismissed, and its care treated as an exaggeration, as reported by some mothers in this stu-

dy who were labeled as too careful or overprotective of their children.

The concept of morphogenesis, from the Family Systems Theory, explains this behavior. The interference of external factors leads to changes and reconstructions in the systems⁽¹⁰⁾. In this case, the misunderstandings of people with regards to this condition leads mothers to avoid contact and adapt the routine of their entire family unit to reach one objective: avoiding frustration and the exposure of their children to the risk of reactions⁽¹⁰⁾.

The mothers report difficulties in dealing with the fact that children with this type of allergy, as they grow, start wanting to eat different foods. Consequently, as these children grow older, psychosocial disorders become more frequent, and are related to factors such as anxiety and bullying⁽¹³⁾.

Mothers frequently reported fear of crossed contamination in the industrial production processes or in the preparing of foods in restaurants, as well as fear of not identifying the presence of the allergen in the foods. This corroborates the results of a study that found that approximately 16.0% of allergic reactions are results of misreading food labels or crossed contamination. Food product labels must contain, expressed clearly, an indication of the presence of cow's milk protein⁽¹⁵⁾. It stands out that the new resolution from the National Agency of Sanitary Surveillance addresses the demands regarding labeling industrialized foods⁽¹⁶⁾, which is an advance in the protection of the health of consumers with food allergies.

It is important to highlight that even children who are exclusively fed with breast milk, depending on the diet of the mother, can present allergic reactions to the proteins in cow's milk and, in these cases, diagnosing is even harder⁽¹⁷⁾. However, food allergies are no counter indication to breastfeeding, which is recognized throughout the world as the golden standard in food for infants up to six months of age. In Italy, a study investigated the relations between breastfeeding and the IL-10 (an anti-inflammatory marker) levels of the child in 124 children who were accompanied

by their mothers in an immunoallergology unit, and the results found that exclusive breastfeeding induces children with CMPA-related atopic dermatitis to become less sensitive, thus leading to less severe cases⁽¹⁸⁾.

Therefore, in the case of children with CMPA, the maintenance of breastfeeding is even more important, but it requires the mother to adapt to a rigorous cow's milk elimination diet, eliminating even by-products and traces of milk's protein. Thus, the mother needs to receive special care, so they can feel empowered to continue breastfeeding. In this regard, as to maintain an integral and humanized assistance, health professionals must consider the particularities and realities of each woman (unit) in biological, social, psychological and cultural terms, while also considering their families. This is how the professionals can understand them holistically(19-20).

Despite the undeniable benefits of breastfeeding, some women cannot maintain it. This happens due to the lack of support, which in turn results from lack of knowledge about this type of allergy, from the complexity of the diet, and from the fear of contamination and its consequent allergic manifestations in the child. In these cases, hydrolyzed forms of cow milk or amino acids should be used⁽³⁾.

The mothers in this study showed knowledge regarding CMPA, which is probably related to the fact that they are highly educated, which allowed them to seek and share information and even to offer informational and emotional support to one another on social networks, which have thus become an important support network. Furthermore, due to the lack of knowledge of some professionals, the information they acquired empowered them and guaranteed that they felt stronger and more capable of dealing with the uncertainties of care.

In this study, through the Family Systems Theory, it was possible to perceive how both the mother (part) and the family (whole) behave with regards to the vicissitudes caused by the illness of one of its members. It became clear that the units (members) are willing to adapt, taking measures such as social

isolation and dietary changes, to reach common goals, well-being, and the quality of life of the system as a whole.

Conclusion

The rigorous food restrictions, resulting from the allergy to cow's milk protein, significantly reverberates in the in the lives of children and families, especially mothers, leading to the social isolation of the family and to insecurity in the use of health and education services, due to the lack of knowledge and to the unpreparedness of the professionals.

Collaborations

Reis P and Nass EMA were responsible for data collection, analysis, and interpretation, and for the writing of the article. Batista VC, Marquete VF and Ferreira PC took part in the writing of the article and in the relevant critical review of the intellectual content. Marcon SS and Ichisato SMT collaborated through a relevant critical review of the intellectual content and with the final approval of the version to be published.

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