

## PERCEPTIONS OF CAREGIVERS OF PATIENTS WITH COW'S MILK ALLERGY REGARDING THE TREATMENT

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### Abstract:

The aim of this qualitative study was to understand the perceptions of caregivers of children and adolescents with cow's milk allergy regarding the disease and its treatment. Nine caregivers were interviewed and content analysis method was used. Three categories with subcategories emerged: treatment and education of the patient and their caregivers (life experiences, bases of treatment, coping with the disease), resolution of the disease (hope, gradual improvement), quality of life (social inclusion, family daily activities, costs of dietary treatment). Caregivers experienced difficulties during the initial treatment but pointed out that the guidance given during follow-up made the adjustments easier. Family members commented on the difficulties about lack of cooperation from other family members regarding the restrictive diet, their experience coping with the allergic reaction, doubts about the treatment and gaps on knowledge about the disease by other physicians and people. Some of them believed that there is no treatment for the disease, because there are no drugs or vaccines, but they were waiting for cure. The majority of relatives were satisfied with the gradual improvement of patients observed by reduction on the severity of symptoms and tolerance of milk traces within foods. In addition, they commented on the efforts to give a normal life for their children, the changes in their daily lives and the difficulty to buy special products. Concluding, caregivers of children and adolescents with cow's milk allergy feel a great burden of the disease.

**Key word:** qualitative research; food hypersensitivity; child; milk hypersensitivity.

### INTRODUCTION

Studies have shown that food allergies (FAs) can negatively affect the patients' and caregivers' quality of life (QoL), especially because the management is restricted to dietary exclusion of the implicated food with constant vigilance needed to avoid allergic reactions. Health professionals have an important role in improving the QoL of this population and providing good quality information about the disease and nutritionally adequate substitutes<sup>1</sup>.

In a recent literature review, the authors assessed the psychosocial impact of FAs in children, adolescents and their families. The QoL of some subgroups of patients (females, individuals with a higher number of FAs, individuals with a larger number of previous allergic reactions

or individuals with co-existing atopic diseases) seems to be more adversely affected; the same effect is observed in their caregivers<sup>1</sup>.

Moreover, there is evidence that children with FAs with a previous history of anaphylaxis suffer more than those with other chronic diseases like rheumatologic disease or insulin-dependent diabetes mellitus, probably due to the constant fear of a possible anaphylactic reaction and risk of death, causing high levels of anxiety and stress for the patient and his family<sup>2</sup>.

Despite the importance of this subject, there are few studies in the literature about patients' and caregivers' QoL, most of them involving patients with peanut and/or tree nuts allergies<sup>3-9</sup>. On the other hand, in our country, cow's milk is one of the major allergens in paediatric patients, and even though its exclusion

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from the diet is extremely difficult due to its wide distribution in food products and its nutritional importance in feeding the child, researches that address the problems related to this restriction are still lacking.

Therefore, this study was designed to understand the perceptions of caregivers of children and adolescents with cow's milk allergy (CMA) regarding the disease and its treatment.

## METHODS

A qualitative research approach was chosen to explore this subject because it allows subjective evaluation and emphasises understanding of processes and phenomena experienced (perceptions, motivations, attitudes, values, beliefs and trends)<sup>10,11</sup>.

This study was conducted at the outpatient clinic of FA, Allergy and Immunology Unit from Instituto da Criança do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo (ICr-HCFMUSP), between October 2009 and January 2010.

The study was approved by the ethics committee of the institution (nº. 513/09) and the research was conducted in accordance with the ethical standards required. The participants were informed about the study and signed a consent form.

Participants were family members involved in the care of children and adolescents (under 19 years of age) with confirmed CMA, mediated by immunoglobulin E (IgE), with or without symptoms of anaphylaxis, (clinical history plus laboratory and/or oral food challenge tests) who were followed for, at least, 1 year. The diagnosis of CMA was performed by means of laboratory tests (Skin Prick Test and/or RAST/ImmunoCAP) and/or oral food challenge. We excluded family members or caregivers of children and adolescents with CMA who were not directly responsible for them or caregivers of patients with other chronic non-allergic diseases that affected their activities.

Among the eligible caregivers, those who first arrived at the hospital on the appointment date were selected and one interview per day was collected, before medical consultation, to avoid interference from what was going to be discussed.

Patients' characteristics were collected from medical records, and caregivers' characteristics were obtained at the beginning of the interview using a standardised form. All names were replaced by fictitious names.

Interviews were conducted using a digital recorder, and participants were invited to speak freely about two questions: "Tell me about your experience with cow's milk allergy treatment" and "What do you expect from your child's disease treatment?".

The statements were collected in a previously selected local, without an appointment. There were no other questions or comments made by the researcher.

The interviews were transcribed and afterwards rewritten without grammatical errors or meaningless words, as a possibility to go beyond mere data acquisition in favour of the possibility of more subjective experiences of respondents<sup>12</sup>.

Data were evaluated by the content analysis method<sup>13</sup>, which is widely used and critically evaluates the meaning of the message, so that, after careful observation, it is possible to critically understand the meaning of the message, whether explicit, hidden or obscure<sup>14</sup>.

Firstly, the meaning units were identified by reading the interviews several times to become familiar with the text and to select the main ideas of each data extract (words, sentences, phrases or passages). The meaning units were coded according to the number of interview (letter D, followed by number) and the order of appearance in the text (letter US, followed by number). Subsequently, Portuguese language dictionaries<sup>15,16</sup> were used to help interpret the message of each meaning unit<sup>13</sup>.

Then, the meaning units were classified according to their similarities and differences into categories, which were interpreted. The number of categories and their names were established by the researchers and checked by a third external researcher.

## RESULTS

We interviewed nine female caregivers, one of which was the child's grandmother. The age of the respondents ranged from 25 to 58 years and the educational level from elementary to post graduation. Family income ranged from 0.4- to 1.7-times the minimum wage per capita.

Four of the children and adolescents were female, and five were male. The average age at the interview was  $7.1 \pm 3.4$  years (from 2 to 12 years). The patients were on cow's milk (CM)-free diets for  $6.4 \pm 3.3$  years and were under follow-up for  $3.5 \pm 2.3$  years at our clinic. The majority of patients had other allergic diseases, and two of them also had adverse reactions to other foods. Concerning the type of allergic reaction to CM, most of them had cutaneous and respiratory manifestations, and seven children had a history of anaphylaxis.

Three categories and eight subcategories emerged from the data analysis: treatment and education of the patient and their caregivers (life experiences, bases of treatment, coping with the disease), resolution of the disease (hope, gradual improvement), quality of life (social inclusion, family daily activities, costs of dietary treatment).

### Treatment and education of the patient and their caregivers: life experiences

Concerning life experiences, caregivers expressed their opinion about the treatment and commented on the knowledge gaps about the disease and the experiences of allergic reactions.

Regarding the treatment, caregivers reported on the beginning of the treatment, acceptance of the diagnosis and the difficulties they had before the follow-up was started at our outpatient clinic. They indicated that life became easier after receiving the orientation, and, because of that, they were very satisfied with the treatment:

*...at first it was very difficult and very complicated because I had never heard of milk allergy until he was born. So, when he was born, I got to come here, and this was where I had orientation about the allergy. (D8US1)*

After starting the follow up, they could understand more about the disease, which greatly facilitated the care of the child.

We also found that after a period of adaptation to the illness, caregivers recognised that CMA was not as severe as other diseases.

In addition to the positive aspects of the follow-up reported by family members, we also observed some complaints, such as the impact of the information in the first visit, dissatisfaction and doubts.

Regarding the first visit, in general, too much information is provided, which may be remarkable in the families' lives and cause feelings of anxiety and fear.

In reference to dissatisfaction, we realised that the treatment does not often meet their expectations. In one interview, the grandmother of a 12-year-old demonstrated her frustration because, in her view, the management was always the same and the visits were not advantageous for the patient, except for the consultation with a nutritionist, in which recipes and new guidance were given:

*Today, I asked myself when I left home. I miss a day of my job... (...) So, I'm questioning myself: "What am I going to do there?" The nutritionist guides me, gives me something (...), and gave me a book about the diet. So, I still see an advantage, but coming here to the doctor... (D5US4)*

The doubts were related to the diagnosis, treatment and natural history of CMA. We observed a lack of understanding about the disease, the need to find the cause of the disease, questions about the existence of other treatment modalities (e.g., vaccines) and whether it is possible to determine the age of tolerance:

*... I don't know if one day she will be able to drink milk. I love milk, so, all the foods that I love, the porridge, she can't eat, so I'm thinking, "Is this going to change?" But that*

*is a question I can't answer, I don't know if doctors can tell me, "she will be able to drink milk in this certain age." (D6US12)*

Despite the confidence in the hospital medical staff, family members demonstrated that there is a considerable lack of knowledge by other physicians and by the population about CMA.

We observed bad experiences with other family physicians, due to receiving prescriptions for medications containing lactose or having trouble in the emergency room due to an anaphylactic reaction:

*(...) This time, he arrived at the emergency room sick. We were lucky because the doctor was very nice. They tended to him first because he arrived there breathless, purple, purple within the mouth, all red, with wheezing. (...) The emergency room doesn't always tend to children or the person who is the sickest first. (...) This time I was lucky because as soon as I arrived there, I had not even filled out the form, and they were already tending to him, giving him a shot and fluids. (D5US8)*

There were also reports of conflicts with the child's father, by blaming the mother for developing the disease, attributed to genetic inheritance and for not supporting the elimination diet.

*At first, I had difficulty with his father. Because his father also didn't accept. And until today he says that it's my fault. He says it's my blood that's bad. So there are always those words that often hurt us. You can even forgive, but can't forget, it sticks in our mind. (D4US9)*

One mother said that the people from their neighbourhood did not believe that her son had allergies and offered him CM against her orders. Furthermore, they said to her that he couldn't have CMA because it was considered a "disease of the rich".

*Some of these people who criticized me could see for themselves, because they disobeyed me, they were doing experience with him, and they suffered the consequences. Of course I was very sad, but they also learned to realize that was not bullshit, it was serious. (D4US7)*

As for the allergic reactions experienced, we observed lack of training of family and health professionals, because they could not accomplish the necessary steps for the treatment of reactions.

*... I had a problem on the airplane because she ate a crust of bread and had an anaphylactic reaction, and I got really upset because, high up there, I gave the adrenaline to a doctor, and he refused to give it to her, saying that phenergan would do. It was very embarrassing for us because we cried a lot and could do nothing with her. (D6US8)*

### **Treatment and education of the patient and their caregivers: bases of treatment**

In the subcategory bases of treatment, family members questioned the definition of treatment by relating it to the administration of drugs or vaccines but not with the elimination diet, which was considered only an instruction:

*Until now, I have not seen any treatment. There is no treatment! I come here just to receive guidance. (D5US10)*

We observed the desire to administer a vaccine or medicine to cure the child's allergy, illustrating a direct relationship between treatment and cure.

Our inability to accelerate the acquisition of tolerance, in which food intake does not cause reactions, was also evident. Thus, we can only guide the patients as they wait for the allergy to improve.

### **Treatment and education of the patient and their caregivers: coping with the disease**

Family members stressed the importance of learning about how to deal with CMA; for example, knowing the allowed and prohibited foods, reading labels, receiving recipes from the nutritionist, and preparing meals. They also highlighted the importance of adherence to the treatment by the child, caregiver and school.

*If I don't read all with caution, I stay at risk. Now he is well, one hundred percent good, but before, I had to read very carefully because, otherwise, I put him at risk. First it appeared as wounds on the skin, then started the wheezing and vomiting started. It was everything. (D1US11)*

*In the past, my son said: "You don't make a cake for me mom?" And now I know how to do everything including cake, and to prepare so many recipes without milk ... (D1US24)*

Despite the effort to follow the information from the orientation, a major difficulty observed by mothers corresponded to controlling the feeding of young children, especially when they had siblings, because the child wanted to eat the same foods as the other children:

*It's because he doesn't understand. Sometimes it is very fast. I also have an 8 year-old girl. So she hides herself to eat things. If my son sees an empty package, he already knows. He wants it. I tell him: "No, Alexandre, you can't eat it." Then he screams, cries until he vomits from crying. So I think now, at this age it is harder for me to control. It's very difficult. (D3US5)*

However, as the child grows old, she starts to understand her condition and also helps in treatment adherence. This awareness of the child is a factor of tranquillity for the mother and facilitates adherence to exclusion diets.

When starting school, teachers and other staff involved have key role in collaboration with the treatment:

*And the school, particularly because he stays 9 hours in school. So the school knows what he can and what he can't. (D3US4)*

*The teens may be aware of the exclusion diet, but not necessarily adhere to treatment, which can cause concern to family members: He leaves home, he goes to a birthday party, (...) I pray for him. Look: "don't eat cake, (...) nothing that they have there." The chips, depending on the chips, if (...) it has milk in it, he gets sick. (D5US7)*

We also realised that caregivers might view the exclusion diet either positively, believing they are providing healthier foods, or negatively, believing that the child is suffering because he or she could not eat some prohibited, desired food:

*I know there are many things, foods, sweets, she doesn't eat that for many mothers, they would think "Oh, I'm sad, she goes to a party, and she doesn't eat. "I don't think like this today. Today, I think that what she eats is very healthy. She has a very nutritious diet. (D6US4)*

### **Resolution of the disease: hope**

Family members commented on the desire for a cure, meaning the acquisition of tolerance. We realised that they knew about the increase in the chances of tolerance with age and that it was dependent on the child's own body.

*What I hope, maybe in two to three years, even more - I don't know, it depends a lot on his body - is that he will be one hundred percent good... (D1US15)*

Mothers also described clearly the natural aspect of hoping for the best as part of the role of being a mother, i.e., they cared about their children and their well-being.

Moreover, the hope for cure helped mothers to cope with the disease, believing that tolerance would be acquired with the follow-up treatment.

### **Resolution of the disease: gradual improvement**

Positive aspects observed were satisfaction with the decrease in the number of allergic reactions:

*... thank God, I see a great change. Previously, no one could touch him; he went into an allergic attack. Now, this doesn't happen. He can go to school, and he has meals with everybody. So, I see that it is getting better. (D8US4)*

We also noted the satisfaction about the gradual improvement, for example, the reduction of the severity of symptoms, tolerance for traces of milk, and the possibility of going to school and having a meal in the company of friends.



Family members are aware that there is an evolution during treatment, but it is slow and gradual. Just like walking and talking are big achievements celebrated by parents, we realize that being able to eat foods with traces of milk and have meals with friends is also celebrated:

*Now she knows because she eats a little bit, and because it is starting to get better. Everything is like it was for the first time, walking, talking, standing up. Now, it is better. (D9US7)*

We found that the mothers' speeches were laced with faith in God, and thus, they had hope of improvement and more easily overcame the problems confronted in everyday life:

*... I pray a lot to God, for him to get better, in the first place. Because when I started coming here, the treatment, he was almost 1 year old, I think. And I'm there, for better or worse, we'll see. (D3US9)*

### Quality Of Life: social inclusion

Family members commented on their efforts to promote normal lives for their children in hopes that they could live like other children by attending school and eating the foods they wanted with no exclusions.

*... I do everything for her to live well. (D6US11)*

In addition, specialised follow-up visits provided support and guidance so the children could improve their lives, even when coping with undesirable situations, and with this, caregivers realised that the children could live well.

*As many restrictions as she has, I have tried to adapt her life so that she feels better and not excluded. The doctor in my city didn't want me to put her into school, but I did not agree. I had problems in school, but here, you gave me strength and told me "Go, you have to put her in school to study. She is normal." (D6US5)*

### Quality of life: family daily activities

Family members commented on concerns about taking care of the child, employment, and the fear of an allergic reaction. Giving up a job demonstrated the mother's sacrifice of her own interests on behalf of the child. As for those who worked and left the child alone, it was stressful to think that something unexpected could happen and they would not be able to help.

*My life has two parts: before Joana and after Joana. After she was born, I had many barriers, and my life is now dedicated to her. This year was the year I really started working again because since she was born with this problem, it has been difficult. (D6US1)*  
*My fear is that while I'm working, he's alone. If he does something stupid, no one will be there to help. That is my fear. (D5US9)*

### Quality of life: costs of dietary treatment

Only one mother complained about the financial difficulties of buying food, the lack of products near her home and the need to visit multiple stores to find these foods.

*...the foods are expensive too. They are very expensive, and where I live, it is a bit complicated to buy them as well because there are supermarkets that don't have them. Then, it becomes a little difficult. The substitute milk is also much more expensive...(D7US4)*

## DISCUSSION

This is the first qualitative study that is based on Brazilian caregivers of children and adolescents with CMA. The results allowed us to understand how families cope with the disease, their histories and hopes about treatment.

The subcategories bases of treatment and gradual improvement were not expected and were not found in other studies. Regarding the bases for treatment, this subcategory is probably a reflection of the degree of understanding of the families studied. Perhaps part of this belief was due to cultural background, associating drugs with treatment and the difficulty in understanding that the elimination diet was also a treatment modality. Regarding the gradual improvement, this subcategory may not have been found in other studies due to the persistence of severe symptoms in the FAs involved, such as allergies to peanuts and tree nuts.

As for experiences, we found difficulty in accepting the diagnosis of FA, as in other Australian study<sup>7</sup> and observed a process of adaptation over time.

We found that the caregivers still had questions about the treatment even after prolonged follow-up. Other authors found that most families of children with FA had an intense desire for information when the disease was first diagnosed<sup>7</sup>. In view of this, it is important for them to establish a good relationship with health professionals to allow an exchange of information in both directions to facilitate successful patient care<sup>17</sup>.

The consultation with nutritionists was highlighted as an advantage of the institution that cares for FA patients, as they provided food alternatives and facilitated the dietary treatment. In addition, family members declared that it was fundamental to follow the guidelines given by the multidisciplinary team, and they thought that parents who did not follow the recommendations were wasting their time attending the appointments. Therefore, the satisfaction with the treatment supplied by the institution and the trust in our team was evident.

However, the caregivers stated that there was still a lack of knowledge about FAs by health

professionals in general and by the population, as has been shown in other studies<sup>18</sup>. Therefore, improving knowledge about the disease and its treatment will provide greater support, safety and QoL for family members and patients with CMA<sup>18</sup>.

The orientation to the treatment should be practical, to help with the meal planning and to facilitate the adherence to the treatment. One of the essential orientations is reading labels, a difficult task, due to the existing number of words related to milk, to the letter sizes in labels and to the legislation in Brazil<sup>19</sup>.

In this context, the role of the dietician in the multidisciplinary team dealing with patients with CMA is crucial, facilitating the understanding of labels, and because of the constant search for variations in the constituents of products of everyday use and by updating lists of products that should be avoided by consulting services along with customer service for each food industry. Her function is not restricted only to provide income alternatives but to educate patients and families in order to add in their routines all the steps that refer to the care with feeding.

The support of all involved with the patient is fundamental. To help mothers, the main caregivers, the orientation should be extended to other family members (fathers, grandparents, uncles) and caregivers (teachers, neighbours), and whenever possible, their presence should be requested to the medical visit or informational materials should be provided for them.

It is important that caregivers are educated about the natural history of CMA and the acquisition of milk tolerance, realising that the disease usually does not persist for the patient's entire life and that the treatment is often performed for a limited period. In this regard, other studies have shown that religion and spirituality were present in families of children with other chronic diseases, providing feelings of comfort, hope and support for acceptance of the conditions imposed by the disease<sup>17</sup>.

Due to the visible perception of positive evolution, we did not observe reports of

exhaustion, tiredness or depression that have been reported in other studies of patients with chronic diseases<sup>20</sup>, which encourages us to continue the multidisciplinary work performed in our department.

In relation to social inclusion, it is important to highlight that the relatives in our study were concerned with their children's QoL and strived for them to have a normal life, which may have had positive repercussions for the child.

We observed changes in family life, especially the routines of the mothers in our study, who stopped working to take care of the allergic child and complained about financial difficulties in purchasing special foods.

In a study conducted in New Zealand, participants also reported an increase in the cost of living, including doctors, acquisition of self-injectable epinephrine and allergen-free foods<sup>21</sup>. Many participants reported a need to look for special foods in different supermarkets. These costs were also cited by the participants of other Canadian study<sup>6</sup>.

Despite the increased supply of food products intended for patients with CMA, the high price does not allow them to be accessible to people with less purchasing power, which can cause impairment in QoL.

The experiences of caregivers of patients with CMA may be variable depending on the specific scenario. In general, we observed satisfaction with the treatment provided by our institution, but there are problems with other health professionals, family and friends, in addition to the difficulties of dealing with the disease on a daily basis. There are doubts about the disease and a lack of understanding that CMA treatment does not involve the use of daily drugs. Despite the limitations imposed by the disease, there is hope for an improvement and cure and efforts to provide a good QoL.

In our view, the best method to understand the perspectives of caregivers and patients with CMA is by hearing their voices in the broadest sense of the psychosocial aspects involved.

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