

Knowledge of industrialized dairy products labels by parents of patients allergic to cow's milk

Conhecimento da rotulagem de produtos industrializados por familiares de pacientes com alergia a leite de vaca

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ABSTRACT

Objective: To evaluate the ability of relatives of patients with cow's milk allergy to identify terms related to cow's milk on labels of manufactured products.

Methods: Cross-sectional descriptive study based on interviews with relatives of patients with cow's milk allergy. Initially, a questionnaire about the habit of reading labels and the identification of terms related to cow's milk was applied. Next, 12 original labels of manufactured products were shown to the interviewees so that they could decide whether to exclude or not those products from the patient's diet.

Results: Of the 52 interviewees, 80.8% were mothers and 79.0% had at least 8 years of schooling. The median time of follow-up after receiving information about exclusion diet was 2 years and 7 months (from 3 months to 17 years and 6 months). The habit of reading labels of foods, drugs and cosmetics was reported by 57.7, 59.6, and 46.2% of the relatives, respectively. Among the allergic reactions during follow-up, 39.5% were related to mistakes when reading labels. Lactose, casein, and caseinate were the terms identified by 92.3, 38.5, and 23.1% of the family members, respectively. Lactate was interpreted as presence of cow's milk by 51.9% of the interviewees. During the second phase of the study, family members identified lactose (55.8%), casein (26.9%) and caseinate (5.8%) as related to cow's milk.

Conclusion: There was a deficient understanding and identification of cow's milk-related terms in spite of previous counseling. It is important to improve labels and to establish new strategies that allow lay people to identify labels of products containing cow's milk.

Key-words: Food hypersensitivity; milk hypersensitivity; food labeling; parents; knowledge; manufactured foods.

RESUMO

Objetivo: Avaliar a capacidade de identificação dos termos relacionados ao leite de vaca em rótulos de produtos industrializados por familiares de pacientes com alergia à bebida.

Métodos: Estudo transversal, descritivo, baseado em entrevista com familiares de pacientes. Inicialmente, aplicou-se um questionário sobre o hábito de leitura de rótulos e identificação de termos relacionados ao leite e, posteriormente, apresentaram-se rótulos de 12 produtos industrializados para que os familiares decidissem sobre a sua exclusão da dieta do paciente.

Resultados: Dos 52 entrevistados, 80,8% eram mães e 79,0% apresentavam nível médio ou superior de escolaridade. A mediana do tempo em seguimento já com orientação para dieta de exclusão era de dois anos e sete meses (três meses a 17 anos e seis meses). A leitura habitual de rótulos

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de alimentos, medicamentos e cosméticos foi relatada por 57,7%, 59,6% e 46,2% dos familiares, respectivamente. Entre as reações alérgicas ocorridas no seguimento, 39,5% foram relacionadas a erros na leitura de rótulos. Lactose, caseína e caseinato foram os termos identificados por 92,3%, 38,5% e 23,1% dos familiares, respectivamente. Lactato foi interpretado como presença de leite de vaca por 51,9% dos entrevistados. Na segunda etapa, os familiares identificaram a lactose (55,8%), a caseína (26,9%) e o caseinato (5,8%) como substâncias relacionadas ao leite.

Conclusões: Constatou-se deficiente compreensão e identificação, por parte dos pais, dos termos relacionados ao leite apesar das orientações recebidas. É fundamental a adequação da rotulagem e a adoção de novas estratégias para orientação da leitura de rótulos, possibilitando a busca e a identificação de produtos que contenham leite de vaca.

Palavras-chave: hipersensibilidade alimentar; hipersensibilidade a leite; rotulagem de alimentos; pais; conhecimento; alimentos industrializados.

Introduction

Food allergy consists of a set of clinical symptoms secondary to immunological mechanisms triggered by intake, inhalation or contact with certain foods, affecting between 3 and 4% of the adult population and 8% of children younger than three years old⁽¹⁻³⁾. In Brazil, a telephone survey with pediatric gastroenterologists, who reported on their patients with food allergy, showed a prevalence of 7.3%⁽⁴⁾.

Among the most frequent food allergies in the pediatric age group, the most important one is cow's milk allergy (CMA). Prevalence of CMA in children ranges between 2 and 7.5% during the first years of life in developed countries⁽⁵⁾. A study conducted in the USA showed that 41.7% of the cases of food allergy in children were related to cow's milk⁽⁶⁾ and, in Brazil, the telephone survey mentioned above revealed a prevalence rate of 5.7%, accounting for 77% of food allergies in the pediatric age group⁽⁴⁾.

The main allergens of cow's milk are glycoproteins with molecular weight between 10 and 70kDa, and the most common allergens are beta-lactoglobulin and alpha-casein, followed by beta-casein, alpha-lactoglobulin, bovine serum albumin, and bovine gamma globulin.

After CMA diagnosis is established, the first measure to be taken is the introduction of a diet excluding cow's milk and its derivatives, as well as foods containing the allergen.

The success of such measure is closely related to the correct exclusion of the allergen, as well as to the patients and caregivers' ability to adhere to a diet that is, at the same time, free of these elements and nutritionally adequate. To reach that purpose, parents and patients need to be informed about the terms that may indicate the presence of cow's milk and about the importance of reading labels, which is a difficult task for many parents.

Currently, 70% of the Brazilian general population reads the labels before buying products, and more than half of them cannot adequately understand the meaning of the information provided⁽⁷⁾. People's understanding is even more limited by the fact that small amounts of components do not need to be detailed on the labels, being presented only as "non significant amounts." In Brazil, the National Health Surveillance Agency (Agência Nacional de Vigilância Sanitária, Anvisa) has established that all kinds of caseinates must be informed on the labels, allowing them to be generally presented as "caseinates."

Due to the difficulties and the importance of providing adequate information to patients with CMA and their caregivers, the objective of the present study was to assess the level of interest and understanding of caregivers and patients regarding the labels of manufactured products containing cow's milk. Other objectives included to assess whether patients under treatment had received previous counseling on how to read labels and whether parents actively tried to find out about the presence of cow's milk and its derivatives in the products offered to their children using the manufacturers' customer services to solve their doubts.

Methods

The present study was conducted at the Outpatient Clinic of Food Allergy, Allergy and Immunology Unit, Child Institute, Hospital das Clínicas, FMUSP, from May 2007 to January 2008. All literate parents and caregivers of patients who came for specialty medical visits during the period of study and who met the inclusion criteria participated in the study. Inclusion criteria were: diagnosis of CMA confirmed by clinical history of anaphylaxis or double-blind placebo-controlled test, with recommendation of exclusion diet suggested by a physician or nutritionist. All relatives received standardized information provided by the same nutritionist. School-age children who could read the labels were allowed to participate in the study along with their caregivers. All individuals accepted to participate in the study. We only

excluded those parents or caregivers who did not meet the criteria described above.

Fifty-two parents/caregivers participated in this study. Subjects were informed about the objectives of the study and signed a written consent form. The study protocol was approved by the Research Ethics Committees of the Department of Pediatrics and of Hospital das Clínicas of FMUSP (CAPPesq), protocol no. 0572/07.

Data collection was performed in two phases. The first phase included the administration of a questionnaire (available upon request) containing personal data questions about the interviewee and the patient, as well as 13 objective questions about the habit of reading labels and the identification of terms related to cow's milk. Question no. 8 presented nine words; four of these words, which should be identified by the interviewee, meant that there was cow's milk in the product: lactose, casein, caseinate, and whey protein.

The second phase consisted of a practical test during which 12 labels of manufactured products were shown to the subjects. Such labels could contain cow's milk or not. The interviewees should inform if those products were allowed in the patient's diet. When the interviewees excluded one of the products, they were asked to identify all the ingredients mentioned in the label that meant presence of cow's

milk and that could be dangerous for the child. The labels included the following ingredients: powder milk, skim milk, milk whey, milk protein, butter serum, cheese, lactose, hydrolyzed casein, and caseinate. On some labels (three out of 12), the following phrase was included: "may contain traces of milk," which the interviewees were also supposed to identify. Among the 12 labels shown to the subjects, only one did not contain cow's milk among its ingredients and should not be excluded by the interviewee.

Results

Fifty-two interviewees were included in the present study (corresponding to 52 patients). Of these, 80.8% (42/52) were mothers of the patients, 9.6% (5/52) were fathers, and 15.0% were other caregivers. Most interviewees had completed high school (54.0%) or had entered the university (25.0%).

Sixty-five percent of the patients were male (34/52) and 60.0% (31/52) were younger than five years old (mean age = four years and ten months; median = four years and four months). Thirty (57.0%) patients were being treated with exclusion diet since they were six months old or younger, and 12 patients (23.0%) had initiated exclusion diet between the age of seven months and one year. Duration of exclusion diet ranged from three months to 17 years and six months (median = two years and seven months). Patients' distribution according to age group showed that 40.0% of the patients were older than five years, 48.0% were between one and five years, and 12.0% were younger than one year (Table 1).

With regard to the duration of the exclusion diet, we found 25.0% of the patients with more than five years of elimination diet, 21.0% had been following an exclusion diet from three to five years, 29.0% from one to three years and 25.0% for less than one year. A relatively high proportion of anaphylaxis was reported, affecting 31.0% (16/52) of the patients.

When asked about previous counseling offered at our unit or at another health care facility regarding how to read labels and how to identify terms indicating the presence of cow's milk on the labels, 73.1 and 65.4% of the interviewees provided affirmative answers to these questions, respectively.

The percentages of affirmative answers regarding the habit of reading package inserts of drugs and labels of foods and cosmetic products were 59.6, 57.7 and 46.2, respectively (Table 2). The answers that reported occasional reading of the labels of such products were not included in the data analysis. The percentages of interviewees who reported that

Table 1 – Distribution of 52 patients according to age group and duration of exclusion diet

	Patient's age	Duration of exclusion diet
	n (%)	n (%)
<1 year	6 (12)	13 (25)
1-3 years	14 (27)	15 (29)
3-5 years	11 (21)	11 (21)
>5 years	21 (40)	13 (25)

Table 2 – Frequency of the habit of reading labels of foods and cosmetic products and package inserts of drugs reported by the 52 interviewees

	Labels of foods	Package inserts of drugs	Labels of cosmetic products
	n (%)	n (%)	n (%)
Yes			
Always	30 (57.7)	31 (59.6)	24 (46.2)
Occasionally	20 (38.5)	11 (21.2)	9 (17.3)
No	2 (3.9)	10 (19.2)	19 (36.5)

they never read labels were as follows: 36.5% for labels of cosmetic products, 19.2% for package inserts of drugs, and only 3.8% for labels of foods.

Among all interviewees, 48.1% (25/52) reported they never had doubts while reading labels and 48.1% reported occasional doubts. In cases of doubts, the main measure taken was the exclusion of the product from the child's diet (71.2% – 37/52 did not offer the product). Customer service was used by only 15.4% (8/52) of parents/caregivers. When asked about their behavior when coming across the phrase “contains traces of milk” on the label of the product, 21.2% (11/52) answered they would include the product in the child's diet in spite of that and 78.8% (41/52) said they would not include it. During the practical test, only 30.7% (16/52) of the interviewees of the group that would not include the product containing traces of milk correctly excluded all products showing the warning “traces of milk.”

During exclusion diet, only 26.9% (14/52) of the patients did not have any allergic reaction to a manufactured product. The remaining 38 patients had one or more allergic reactions. The reasons reported by the interviewees for incomplete adherence to the diet were: products offered in school or outside school by relatives or other people who were not aware of the child's allergy (39.6%), product consumed by the child without parental permission (15.8%), failure to read the label of the product (21.1%),

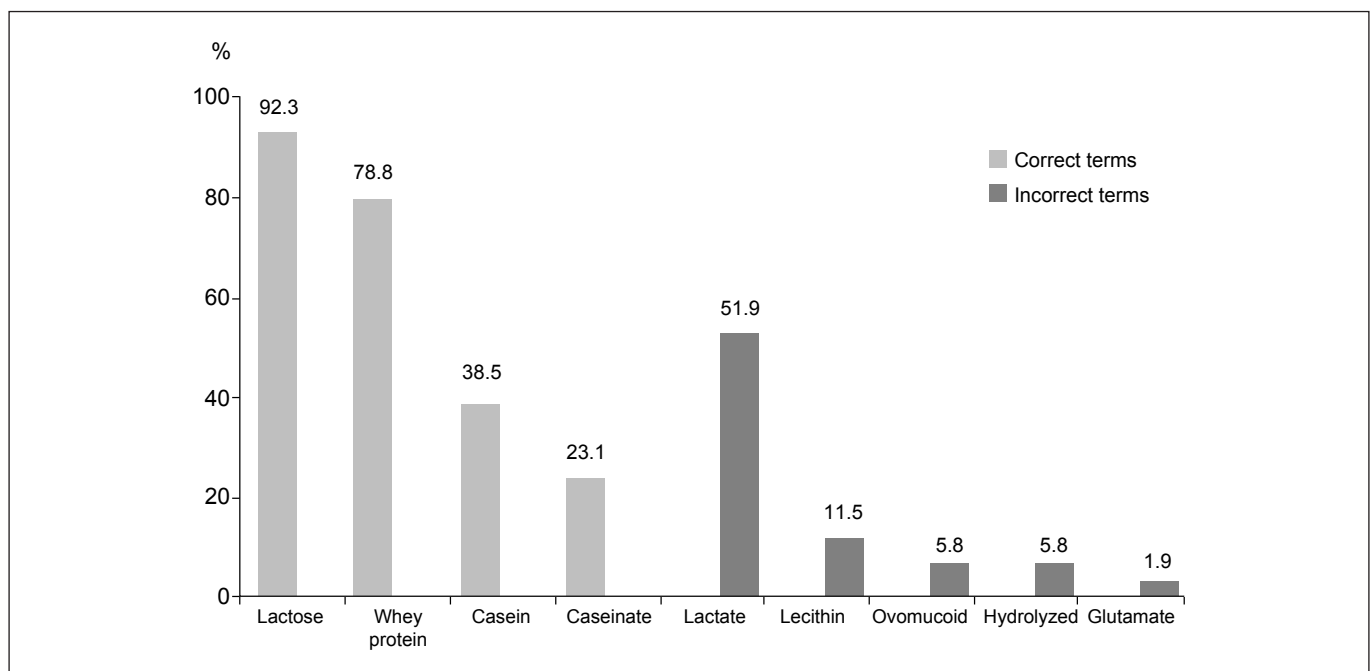
misunderstanding or deficient understanding of the content of the label (18.4%), and product consumed by the mother while the child was still being breastfed (2.6%). One interviewee reported being unaware of the reason for the child's lack of adherence to the diet.

Graphic 1 shows the percentage of correct answers regarding the terms that could or could not mean cow's milk (question number 8). Graphic 2 shows the percentage of identification of terms related to cow's milk in the practical test. We found that 55.8% (29/52) of the interviewees correctly identified lactose and 53.8% (28/52) identified milk. A smaller percentage of interviewees identified caseinate and butter (three out of 52 interviewees – 5.8%) on all labels that included these terms. Only one interviewee was able to exclude the 11 labels by correctly identifying all terms.

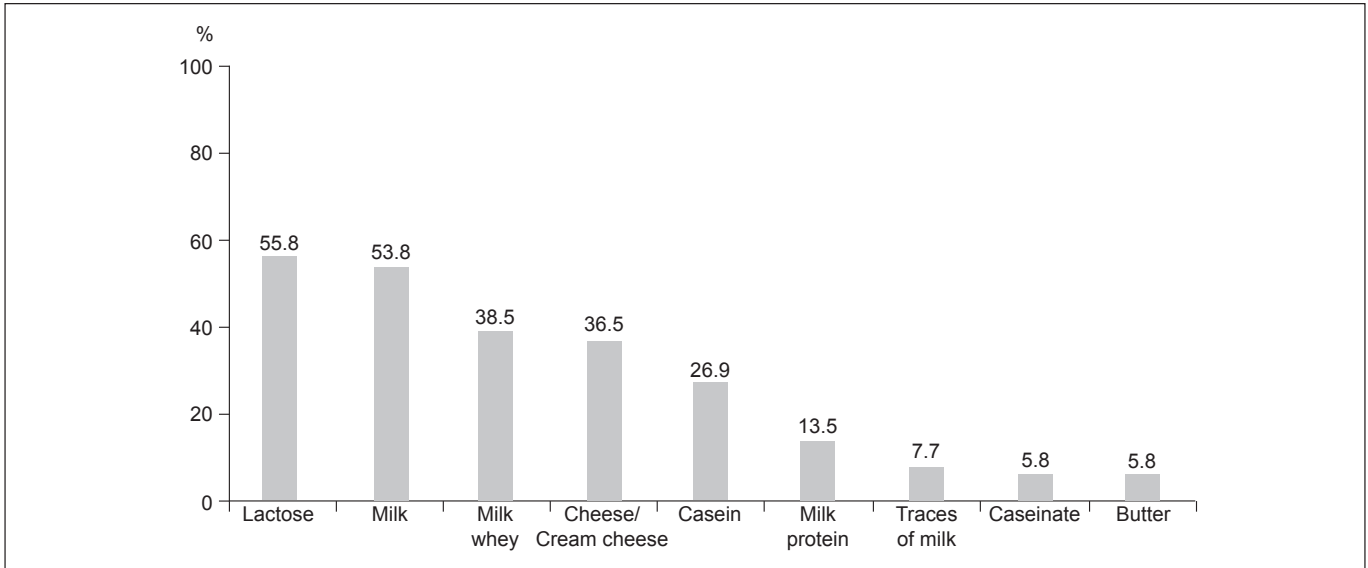
During the assessment of agreement between the answers provided in the first phase (theoretical questionnaire) and in the second phase (practical test) regarding the terms lactose, casein, caseinate, and protein/whey, we found a higher percentage of correct answers in the theoretical phase compared to the practical phase, as shown in Graphic 3.

Discussion

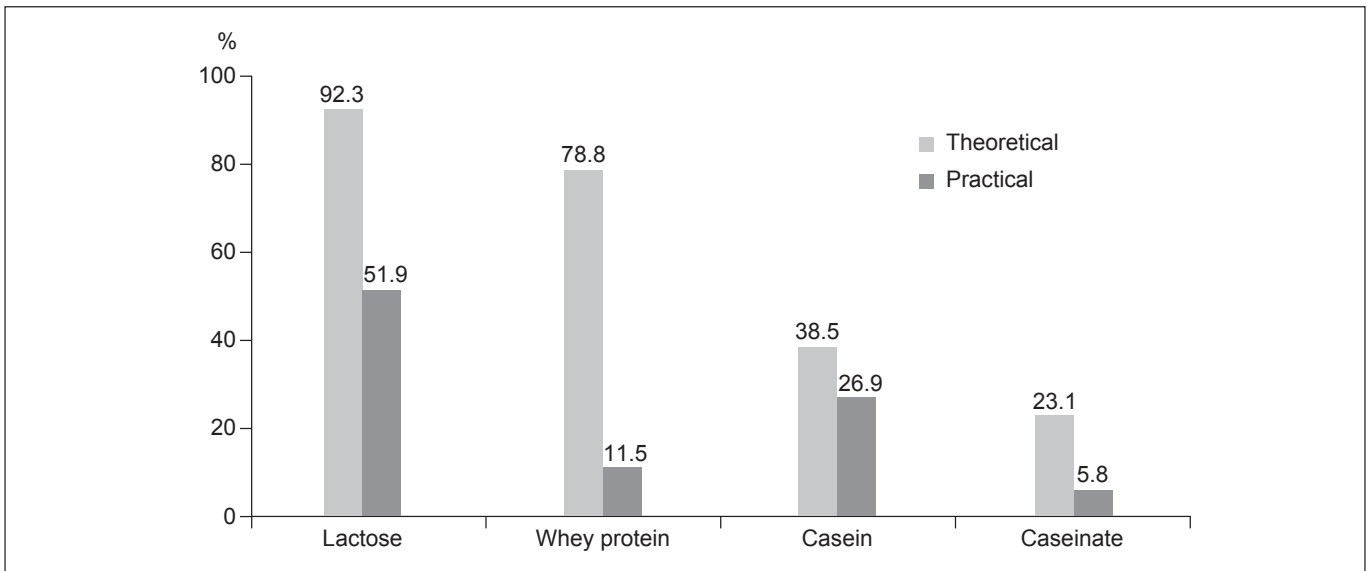
Few studies on food labeling and its relation with the difficulties of establishing a correct treatment for patients



Graphic 1 - Percentage of related terms with cow's milk correctly or not used in the theoretical phase of the study among 52 interviewees



Graphic 2 – Percentage of identification of terms related to cow's milk used in all labels containing cow's milk among 52 interviewees



Graphic 3 – Percentage of agreement between the correct answers regarding the terms used in the theoretical and practical phases of the study among 52 interviewees

with food allergy can be found in the literature. A review of the literature carried out in Brazil including data from 1987 to 2004 reported only 11 studies on the understanding of labels by consumers⁽⁸⁾.

In the present study, we assessed the interviewees' ability to read and understand the labels of manufactured products that could contain cow's milk and that could be easily bought by them. Data related to the patients' age, duration of exclusion diet and the higher proportion of male patients are very similar to those found in the literature^(3,9).

We found that most participants had completed high school or college and had received previous counseling on how to read the labels and identify the terms that could mean presence of cow's milk. Considering these aspects and the fact that our health care facility is a specialized outpatient clinic, where all patients receive medical and nutritional guidance when beginning treatment, we may assume that the percentages of correct answers found in both phases of the interview were lower than expected, revealing poor retention of the information provided.

Joshi and Sicherer reported cases of anaphylaxis in up to 42% of the patients with food allergy being treated with exclusion diet⁽³⁾. In the present study, the relatively high proportion of patients with at least one anaphylactic reaction (31%) indicates the severity of the allergic status of the patients treated at our outpatient clinic and emphasizes the relevance of adequate retention of the initial information provided.

The rather low proportion of interviewees who always read the labels of foods and cosmetic products and the package inserts of drugs (57.7, 46.2 and 59.6%, respectively), as well as the large number of doubts regarding the content of the labels (48.1%) and the lack of adherence to the diet, which led to allergic reactions (73.1%), suggest that there is a need for improving the counseling provided to parents and patients. These data also show the importance of highlighting the possibility of cow's milk protein being preset in cosmetics and some drugs, since the Brazilian population has not become aware of this fact.

According to Muñoz-Furlog, reading labels should be a habit at three different moments: before buying the product, before storing it at home and before consuming it⁽¹⁰⁾. Such habit should be stimulated, as well as the search for adequate information in case of doubts, especially by using customer services or by contacting physicians and nutritionists. Such measures were only taken by a small number of interviewees, but would prevent the exclusion of a product without an appropriate clarification, leading to the correct identification of terms related to cow's milk.

Some studies have reported similar difficulties among parents and patients while reading and interpreting the contents of labels. In a study carried out in the USA in 2006, Joshi and Sicherer assessed parents and patients' ability to identify foods that should be excluded from the child's diet by label reading. Among the terms included in the study (milk, soya, egg, peanut, and wheat), those related to the presence of cow's milk, such as casein and dairy, were the least identified, and only 7% of the parents were able to identify the 14 labels containing cow's milk⁽³⁾. Simons *et al* reported that 16% of the allergic reactions during exclusion diet occurred due to misunderstanding of a term listed among the ingredients, while 22% occurred due to the presence of allergenic components not included on the label⁽⁹⁾.

In Brazil, a recent study revealed that the difficulty in identifying specific terms related to cow's milk, such as casein, alpha-lactalbumin, and beta-lactalbumin, even by parents who have received previous counseling, is very

frequent; the authors of the study highlighted the importance of providing continuous guidance to patients under treatment⁽¹¹⁾.

Regarding the results of this study, based on the comparison between the answers provided to the theoretical questionnaire and in the practical test, which was much more difficult for the interviewees, we identified the extreme relevance of highlighting the specific terms related to cow's milk that parents are not familiar with, such as casein and caseinate. In addition, the difficulty in taking the practical test begins with the task of finding information. Many parents were not able to find the list of ingredients and based their decision on the general label, on the appearance of the label or on the brand of the product. Parents who looked for the ingredients often had difficulties due to the small size of the letters and the great amount of terms listed, while possible allergens were not highlighted on most labels. An aspect that must be emphasized is that the present study can be replicated in other centers of excellence in food allergy, using the same questionnaire administered in our study with other populations characterized by different sociocultural levels.

Based on these data, we detected the need for developing new strategies of counseling in which not only oral information is provided, but also a list of terms that may indicate the presence of cow's milk. Therefore, the exposure of caregivers to original labels during counseling seems to be an important measure to make it easier for them to understand data and look for information on the labels, thus avoiding lack of adherence and reducing the risk of severe reactions during treatment.

Another important aspect is the identification of the need to improve food labeling in terms of how ingredient information is presented. There is a current trend, mainly in developed countries, to discuss changes in the legislation aimed at defining the rules for food labeling of manufactured products. Such measure has been taken to fulfill the higher demand of consumers with food allergy, who have been claiming that labels should present complete information, including the list of all ingredients, and that such information should be easily found and recognized⁽¹²⁾. In the USA, since 2006, industries are required to inform about common allergens (egg, milk, peanut, soya, wheat, chestnuts, and seafood) in a clear manner, using simple language, on all labels^(9,13). The European Commission, based on the recommendation of the Codex Alimentarius Commission, suggested an amendment with the purpose of guaranteeing

that consumers are informed about all ingredients of manufactured products, making it easier to identify food allergens. This amendment requires that ingredients are mentioned even when its amount accounts for less than 25% of the final product, a requirement that also includes alcoholic beverages^(9,12,13).

It would be very useful if the manufacturers included not only the table containing nutritional information but also the list of ingredients, in a way that they could be easily identified by consumers, i.e., using large letters, presenting objective information and using easily understandable language. Taking into consideration the high prevalence of food allergy in the pediatric population, mainly CMA, there might be necessary to include a mandatory warning about potentially allergenic ingredients on labels. Such measure has already been taken by some manufacturers that include an item called "information on allergens" at the end of the list of ingredients. Another interesting method of warning would be the design of an easily identifiable symbol that could help consumers to identify products containing cow's milk or other common food allergens

among the ingredients, similarly to what has been done regarding wheat.

It is important to highlight that the increasing use of the phrase "may contain" by manufacturers, rather than specifying the ingredient, may often cause harm and confound consumers, who end up consuming extremely limited diets^(12,13). For consumers with any kind of food allergy, it would be preferable if the labels showed detailed information on the ingredients of the product in a clear manner.

Finally, the results of the present study allow us to conclude that the understanding of relatives and patients regarding labels of manufactured foods containing cow's milk is deficient due to the lack of clarity and accuracy of labels and insufficient counseling provided by physicians and nutritionists. Improving the identification of ingredients depends on changes in the legislation about food labeling and on new counseling strategies, including the promotion of the use of customer services and techniques of label visualization that help consumers to become familiar with labels and facilitate the search for ingredients that might indicate the presence of cow's milk.

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