

# Milk allergy school: Nutritional therapy in group for parents of children with cow's milk allergy/intolerance in Primary Health Care

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The objective of this study was to create a method for group nutritional therapy for parents of children with cow's milk allergy/intolerance in a paediatric primary care setting to increase accessibility to nutritional therapy. A second objective was to evaluate a milk allergy school. Follow-up time after the group session was 3 yr. All parents to newly diagnosed children ( $n = 98$ ) with cow's milk allergy/intolerance in the Primary Health Care system in the city of Göteborg during an 11-month period were invited. The majority of the families chose to participate ( $n = 84$ , 86%). The mean age of the children was 9 months (3 months to 5 yr). The number of participants obtaining nutritional treatment within a month after diagnosis has significantly increased. Seventy-four families (88%) could be re-contacted 3 yr after participation for a second evaluation. Seventy-eight per cent of the children no longer had cow's milk allergy/intolerance. Most participants expressed satisfaction with the information obtained in the meeting. The milk allergy school does not replace but complements individual counselling. The milk allergy school seems to meet the families' needs for information, has few administrative routines and is cost-efficient. This activity has become permanent, is being offered weekly and can be recommended.

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Cow's milk protein is the most common food related allergy/intolerance among infants (1, 2). Between 2 and 3% of infants in Scandinavia suffer from this condition (3–5), which not only affects the child and its family, but also others involved in the child's everyday life. Consequently the number of individuals in need of information and support can be considerable (6, 7).

The treatment is a strict milk free diet, at least initially for the infants, as well as for the lactating mothers when necessary (8, 9).

In general, the goal of nutritional therapy is twofold: to minimize symptoms through withdrawal of offending allergens and to prevent nutrient deficiencies. An additional role of the dietician is to protect and encourage the social aspects of meals both in the home and in the community (10).

Increasing demands for cost-efficiency from the public health administration has resulted in a search for different working methods in nutrition as a complement to clinical visits to the doctors and dieticians. Interactive nutrition education has been found to increase skills and self-efficacy in participants (11, 12). Systematic and structured parental education has been successfully used for parents of children with atopic dermatitis (13, 14). However, in the treatment of food hypersensitivity, individual counselling is the most usual working method (15).

The aim of this study was to develop a suitable form of group education for families with children suffering from cow's milk allergy/intolerance and to evaluate this intervention immediately after participation and 3 yr later. A secondary aim was to compare time between

diagnosis and nutritional treatment in cases before milk allergy school started, during the milk allergy school's first year and its third year of existence.

### Materials and methods

#### Description of studied children

Families of 98 children diagnosed or suspected to have cow's milk allergy/intolerance in the Primary Health Care system of Göteborg, and prescribed a cow's milk free diet were invited to participate in the milk allergy school between January and November 1999. The parents received written and oral information regarding the aim and content of this milk allergy school, held by a dietician (AM). If the parents or any other responsible adult accepted the invitation they attended the group session without any further medical notification or referral.

#### Organization and curriculum of the group sessions

Based on the number of infants receiving the diagnosis of CMA/CMI in the primary health care organization in Göteborg, the number of participants to the milk allergy school was expected not to exceed 10 in each session provided the meetings were organized at fortnight intervals. This was considered an appropriate number to ensure active participation in accordance with recommendation for nutritional therapy in group (11). At the group sessions, participants were encouraged to narrate how the cow's milk allergy/intolerance was diagnosed, for how long they had been pursuing milk free diet, and what they experienced as major problems in their new situation. This served as a natural starting point to discuss everyday problems resulting from the prescribed diet. The dietician provided information, answered questions, corrected eventual misconceptions and kept the discussion on track. The group session also included practical exercises such as reading ingredient labels from a mix of packages common in a regular household. Participants were also given written instructions on how to follow a milk free diet and booklets of recipes prepared by the dietician and the manufacturers of the milk substitute.

#### Evaluations

A questionnaire survey was conducted to evaluate the performance of the milk allergy school. The survey included structured as well as open-ended questions. After the sessions, participants

were asked to complete the survey form at home and post it back in a stamped envelope. Two weeks later, participants who still had not sent their answers were given a reminder by phone. Two weeks later, all remaining non-responders were contacted by telephone again and given the questionnaire orally.

A second evaluation was performed 3 yr after participation. This time the parents were interviewed by telephone by a structured protocol. The focus of the evaluation was the overall impact of the milk allergy school and the child's disease development over time.

#### Comparison groups for analysis of accessibility to nutritional therapy

In order to evaluate the milk allergy school's effect on accessibility to treatment, a comparison was made of the time elapsed between diagnosis and nutritional therapy. This was made during three different periods, i.e. during the year prior to the start of the milk allergy school, during the milk allergy school's first year and its third year of existence.

Differences between time elapsed between diagnosis and access to nutritional therapy were calculated by chi-squared test.

### Results

The majority of the families (84 families; 86%) invited by personnel from the paediatric outpatient clinics and well baby clinics, chose to participate in the milk allergy school during the study period. Families of 14 children did not participate and the main reason was that they considered themselves as having sufficient knowledge regarding the treatment of cow's milk allergy/intolerance. A total of 122 persons related to 44 boys and 40 girls participated during the first 10 months of the milk allergy school. The average age of the children was 9 months (range: 3 months to 5 yr) and more than 80% were below 1 yr of age. A median of eight families participated in each session (range: 2–13). The most interactive sessions were the sessions with 5–8 families. This was measured in number of questions, comments and contributions from the participants. Most families participated in one session, one family participated twice during the studied period.

#### Symptoms and diagnosis

All children, whose families attended the milk allergy school, had a preliminary diagnosis of

CMA/CMI. The clinical diagnosis was based on history and clinical findings at the time of the examination by the pediatrician. The most common symptoms among the 84 children were skin problems (Table 1). Gastrointestinal and respiratory symptoms were less common. Skin prick test and/or RAST analyses for milk protein were positive in most cases (Table 1). In one case, the diagnosis was confirmed on an elimination and challenge test. The majority of the children did not have adverse reactions to other allergens ( $n = 53$ ). The rest of the children reacted to other foodstuffs, the most usual being egg ( $n = 16$ ).

Cow's milk allergy/intolerance was still present in 12 children at the follow-up 3 yr later (Table 2). The disease status was uncertain in four cases as it had almost disappeared in two children and the diagnosis was under re-evaluation in two. Half the group had developed other food allergies/intolerance (55%). The majority of the children ( $n = 58$ , 78%) were free of symptoms and able to consume dairy products. For this latter group, milk had been successfully introduced into the diet before 3 yr of age, usually at the physician's initiative ( $n = 47$ ). However, 11 families reported that they had introduced dairy products in their child's diet on their own initiative after the child was accidentally exposed to milk in the diet and no reactions were observed. The length of time for introduction of dairy products into the child's diet varied widely. Introduction lasted up to 1 month for

24 children, up to 6 months for 22 children and more than 6 months for two children. This very long introduction was attributed to dislike of dairy products. Nine families performed a gradual introduction of dairy products without specifying for how long a period of time and only in one case did the introduction occur immediately after advice by the physician.

#### Post-session evaluation

The majority of participants indicated at the end of the course that they were satisfied with the content and presentation of information received in milk allergy school (72%). One-third of the participants indicated that their need of information had been only partially met during the session (27%).

These participants could not foresee the future nutritional problems of their children and therefore could not fully agree that the milk allergy school covered all relevant aspects ( $n = 11$ ). Some participants had expected information regarding the diagnosis and prognosis, for instance the risk for anaphylaxis ( $n = 6$ ) which however is not the task for the dietician. All stated that they plan to contact the dietician again when the need for additional information concerning the nutritional treatment arose. A single participant was displeased with the information received. At the 3-yr follow-up the participants' responses showed more positive attitudes including satisfaction with the information received in most cases (88%) and partial satisfaction in only nine cases (12%). Most participants stated that the location (93%), time (87%) and length (82%) for the meeting were convenient.

More than half of the participants preferred to get information both individually and in group (56%). A smaller group (13%) considered it sufficient to attend a milk allergy school, whereas only seven participants (8%) would have preferred individual information. The rest of the participants (23%) did not express an opinion.

Table 1. Reported symptoms and tests performed

Symptoms	Number	Diagnostic test	Number
Skin	41 (49)	Skin prick test (SPT)	39 (46)
Gastrointestinal	8 (10)	Specific IgE (s-IgE)	13 (16)
Respiratory	1 (1)	Elimination/challenge (E/C)	1 (1)
Skin and gastrointestinal	22 (26)	SPT and s-IgE	24 (29)
Skin and respiratory	6 (7)	Other combinations of tests	6 (7)
Other symptoms	5 (6)		
Missing data	1 (1)	Missing data	1 (1)
Total	84		84

Percentage values are given in parentheses.

Table 2. Development of cow's milk allergy/intolerance over time (3 yr) and in relation to other food allergies/intolerance and atopic symptoms

Status of the CMA/CMI	Number	Other food allergy/intolerance						Symptoms			
		No other	Egg	Nuts	Egg + nuts	Egg + other food	Other food	No other	Skin	Respiratory	Comb
Outgrown	58 (78)	30 (40)	11 (15)	4 (5)	4 (5)	4 (5)	5* (7)	44 (59)	5 (7)	6 (8)	3 (4)
Persistent	12 (16)	2 (3)	2 (3)		3 (4)	4 (5)	1 (1)	6 (8)		4 (5)	2 (3)
Uncertain	4 (5)	3 (4)	1 (1)					3 (4)	1 (1)		
Total	74 (100)	35 (47)	14 (19)	4 (5)	7 (9)	8 (11)	6 (8)	53 (72)	6 (8)	10 (14)	5 (7)

Percentage values are given in parentheses.

\*One patient developed celiac disease.

The participants were asked to specify the positive and negative aspects of the milk allergy school. Eighty-nine per cent specified positive aspects while 32% listed any negative aspects, with increasing figures at the follow-up (100 and 34% respectively). Positive aspects included qualities of the given information and support (38%), the encounter with other parents in the same situation (35%) or both features (14%). The most common negative aspect was that the composition of the group was heterogeneous according to age and/or symptoms of the children (11%) as well as level of knowledge among participants (7%). Other negative aspects (14%) concerned the premises and the lack of follow-up activity. Thirteen (18%) families stated the need of a follow-up activity when asked to evaluate the intervention 3 yr later.

#### Time between diagnosis and access to nutritional therapy

During the year prior to the start of the milk allergy school, mean waiting time to the dietician was 33 days (range: 0–152 days). Half of the patients (51%) received nutritional therapy within a month after diagnosis. During the first year of the milk allergy school the mean time elapsed between diagnosis and participation in the milk allergy school was 27 days (range: 1–160) and the proportion of patients receiving nutritional therapy within a month increased to 64%.

In 2003, the mean time elapsed between diagnosis and nutritional therapy was 18 days (range: 0–90 days) during an equivalent 10-month period (October 2002 to June 2003) and 83% of the families participated within a month after diagnosis. Time between diagnosis and nutritional therapy has significantly decreased since the pilot year of the study ( $p < 0.0001$ ).

#### Discussion

Introduction of the milk allergy school in the primary health care organization of Göteborg for parents with children with cow's milk allergy/intolerance resulted in satisfied participants and in addition a parental platform for sharing experiences.

One of the aims with introducing the milk allergy school was to increase accessibility. Although the time elapsed between diagnoses, and participation in the milk allergy school did not decrease as dramatically as expected immediately after the introduction, a large decrease was seen over time. The probable explanation for this delay is that it takes time to introduce

an intervention procedure like this. As the milk allergy school has become well known, participation has increased. The sessions were arranged once a fortnight but are now offered weekly.

Shortening the time between diagnosis and nutrition therapy is of great importance for children on elimination diets, because of the risk of nutritional deficiencies and growth retardation for the child (16, 17). The elimination diet could be harmful for the lactating mother's health as well (18). A milk containing diet causes energy loss because of the sustained allergic inflammation in these children (19). The sooner the parents understand the need of a milk free diet the better are the chances to eliminate or reduce the symptoms of cow's milk allergy/intolerance.

Participants are welcome to return to the milk allergy school, as new questions arise and new situations are encountered in the growing child's everyday life. Interaction between participants provides a valuable resource of information from shared experiences and often ingenious solutions to daily situations, emerging from pursuing a milk free diet. For instance how to manage the introduction and preparation of alternative food for different occasions, visiting restaurants, attending family gatherings, eating with friends, and how to help others understand the need for a strict milk free diet. These factors can increase motivation to accomplish the treatment. To the dietician, the discussion among participants can provide important information concerning the strategies to overcome difficulties, as well as detecting obstacles that might affect diet compliance.

At the 3-yr follow-up 11 families stated that dairy products had been re-introduced in their child's regular diet after accidental intake. We interpret that these children had had a too long elimination period or an unnecessary elimination diet. This emphasizes that the diagnosis should be confirmed through elimination and provocation procedures.

As a result of parental acceptance and increased accessibility, the milk allergy school has become permanent and is being now offered weekly. The number of participants since then rarely surpasses six to eight families making the sessions manageable for the dietician as well as dynamic and rewarding for the participants.

In conclusion, the milk allergy school seems to satisfy most families' need of information and support to manage the milk-free diet. It is an excellent complement to clinical visits to the

physician and the dietician but needs to be further developed and evaluated.

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