

Concerns and expectations of parents with atopic infants

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The incidence of atopic diseases has rapidly increased in developed countries. The purpose of this study was to describe the problems that parents experience when atopic disease occurs in their children at an early age and what parents expect and get from health care professionals in the management of these problems. The parents of 81 high-risk atopic infants completed a questionnaire during the infant's first attendance at the Tampere University Hospital, Finland. The patients were treated by an intervention team comprising a pediatric nurse and two pediatricians consulting with dietician and a dermatologist to detect the infant's specific food allergies and to introduce and advise on appropriate diets at weaning. After a 9-month intervention period, the parents' perception of the intervention was evaluated by a second questionnaire. The skin prick test was positive to cow's milk in 30%, to egg in 26%, and to cereals in 19% of infants during breast-feeding. Double-blind placebo-controlled cow's milk challenge was positive in 56% of infants. Upon introduction of a tolerated weaning diet, subjective symptoms and the extent and intensity of atopic eczema diminished as evidenced by lowered SCORAD scores, from 19.3 to 8.2 ($F = 57.6$, $p < 0.0001$; SCORAD – scoring index combining extent, severity and subjective symptoms of atopic eczema). Ninety per cent of parents found the care of an atopic infant more demanding than that of a healthy child. This was because of the persistence of symptoms, such as atopic eczema and pruritus, and restlessness during sleep. For the management of these problems the parents advocated diagnostic evaluation and elimination of specific foods from the diet of the lactating mother. They expected from the intervention accurate diagnosis of food allergies, practical advice on elimination diets, alleviation of symptoms, and follow-up of growth and nutrition, and they considered the care provided by the intervention team to suffice in these aims. The present data support a comprehensive team approach to the care of atopic infants and their parents.

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Atopic disease is now a major health problem in industrialized countries. Recent reports demonstrate that the prevalence of atopic eczema (1) and asthma (2) have increased. In a Japanese study, an increase of nearly two-fold in the prevalence of allergen-specific immunoglobulin E (IgE) among 13–14-year-old girls was observed over 13 years (3). A positive response in skin prick tests (SPTs) to allergen demonstrates the presence of atopy in $\approx 40\%$ of the population, although not all have clinical disease (4). The first manifestation of atopic disease is atopic eczema, typified by highly pruritic, red, scaly, and exudative patches on the

cheeks, extensor parts, and flexural areas of the extremities (5). The lifetime prevalence of atopic eczema in 6–7-year-old children is 27.8% (6). Approximately 40–54% of children with moderate to severe atopic eczema suffer from food allergy, some with allergies to a variety of foods of dietary importance, for example milk and cereals (7, 8). Increased severity of atopic eczema and younger age of patients correlates directly with the presence of food hypersensitivity (8).

The increase in the prevalence of atopic disease has led to a situation where many families experience problems in the care of atopic infants.

Atopic eczema, pruritus, sleep loss, and gastrointestinal symptoms, together with concern for an optimal diet, may cause stress in the family (9–11). The management of these problems constitutes a challenge to both primary and specialized health care systems.

To our knowledge, the concerns of parents with an atopic infant have not been previously documented systematically. Therefore, the purpose of this study was to describe the problems that parents experience in the care of their high-risk atopic infant and their expectations vis à vis health care professionals. We also wanted to evaluate how our mode of intervention, developed for a previous study on early sensitization (10), met the expectations of the parents.

Patients and methods

Patients

We wanted to describe the problems that parents experience in an extreme situation when atopic disease occurs during breast-feeding. Therefore the initial study population comprised 92 consecutive breast-fed infants who were admitted to the Department of Paediatrics at Tampere University Hospital, Finland, and whose parents consented verbally and in writing to participate in the study. In these infants, atopic eczema fulfilling the Hanifin criteria (12) had begun during exclusive breast-feeding. At inclusion, all parents were given the first questionnaire and 76 were returned (response rate 83%). Four patients discontinued the study: two because of early disappearance of symptoms and two because of severe symptoms requiring hospital treatment. At the last study visit the parents of 88 infants were given the second questionnaire and 74 were returned (response rate 84%). Non-responders were contacted by telephone on two separate occasions (3 weeks apart) in order to encourage them to complete the questionnaire. The number of patients whose parents returned either or both questionnaires was 81, these thus comprising the study population.

Questionnaires

Because no suitable questionnaire was available from the literature, new questionnaires were created for this study by the researchers. The researchers are regularly involved in scientific research and clinical work with atopic infants and the questions asked in the present study arise from experiences of both the researchers and the parents of atopic infants. Prior to the study the questionnaires were pretested with randomly

assigned parents of 10 atopic infants fulfilling the Hanifin criteria. The pretest analysis confirmed that the questions were easy to understand. A study form included structured and open-ended questions. The Lickert scale was used in structured questions. The parents completed the questionnaires during the visit or at home, and in that case, mailed them back to the investigators.

The first questionnaire before intervention concerned:

1. The diet of the infant and the lactating mother at the onset of the atopic symptoms.
2. Problems in the care of the infant before diagnostic and therapeutic intervention.
3. The advice the parents received in primary health care regarding the management of these problems and whether this advice was of benefit to the atopic infant and the family.
4. The expectations from diagnostic and therapeutic evaluation by the intervention team.

The second questionnaire after intervention covered:

1. The parents' perception of the care of the infant by the intervention team.
2. Problems concerning the care of the infant during the diagnostic and therapeutic intervention.
3. The usefulness of the advice that parents received from the intervention team for the management of these problems.
4. The realization of expectations from the diagnostic and therapeutic interventions.

Intervention

Intervention team. The intervention team comprised a pediatric nurse and two pediatricians with expertise in food allergy, who consulted regularly with a dietician and a dermatologist. All decisions were made together with the parents.

Evaluation of sensitization. For evaluating the extent of sensitization, serum total IgE (Phadebas IgE Prist, Pharmacia, Uppsala, Sweden), specific IgE (radioallergosorbent test – RAST), and SPTs for dietary antigens were studied. One month after the cessation of breast-feeding, cow's milk allergy was diagnosed by double-blind placebo-controlled food challenge, as previously described (7). Briefly, the patients were randomized by means of a computer program

to receive placebo formula, which was the amino acid-derived Neocate (SHS Int., Liverpool, UK) or the test formula, which consisted of Neocate and 100 g/l of cow's milk powder. On the first day of the challenge, increasing amounts (1, 5, 10, 50, and 100 ml) of the allocated formula were given at 30-min intervals. The challenge period was 1 week for both placebo and test formula. The parents and researchers were unaware of the nature of the administered formula. Cow's milk allergy was defined as an unambiguous adverse reaction to the test formula. After negative challenge, the patients were followed-up on open consumption of cow's milk. The patients were re-evaluated 1 month later to confirm the diagnosis and to exclude delayed reactions to the challenge.

Dietary intervention. The foods suspected to cause allergic symptoms (on the basis of clinical history, specific IgE, and SPT results) were eliminated from the patients' diet and substituted with nutritionally equal foods. At weaning, a clinically tolerated hypoallergenic formula was introduced to the infants. Tolerance was confirmed at subsequent clinical evaluations.

Study visits during intervention

The mean total duration of the intervention period was 9 months (range 5–15 months). Breast milk comprised the major source of nutrition at the first visit. The second visit was arranged after the mothers stopped breast-feeding. During every study visit all patients were evaluated as follows: they were clinically examined and the severity of atopic eczema was scored according to the SCORAD method [SCORAD is a scoring index combining extent, severity and subjective symptoms of atopic eczema] (13) by the same pediatricians. The parents were interviewed verbally regarding recent symptoms in the infant and concerns of the parents. The parents were given a list of new foods to be introduced to infants in increasing amounts if no symptoms appeared. Compliance to the recommendations was assessed by monitoring of growth as poor growth is assumed to be caused by sustained allergic inflammation (14). During the intervention, all families visited the pediatric nurse and the pediatricians six times, a dietician twice (when nutrient intakes were calculated and the patients received individual dietary guidance), and a dermatologist once (when the SPTs were performed and the patients received advice on skin treatment). The visits to the dietician and the dermatologist were made on the same days as the

visits to the pediatricians and the pediatric nurse, so that each family visited the hospital six times during the follow-up. The pediatric nurse gave practical advice on elimination diets and was available for any enquiries concerning the care of the patients and for the support of the families throughout the study. At the final study visit the patients were referred for further follow-up if deemed necessary on clinical grounds.

Statistics

The results are presented as means with 95% confidence intervals (CI) or with range, when appropriate. The chi-square test and analysis of variance for repeated measurements were used in statistical comparisons.

Ethics

Written informed consent was obtained from the parents of the children, and the study was approved by the Committee on Ethical Practice of Tampere University Hospital.

Results

Clinical characteristics of the patients

The patients' atopic eczema had begun at a mean age of 2 months (range 0.5–6 months). At that time all patients were exclusively breast-fed and they had never ingested any cow's milk-containing formula or cereals (wheat, rye, barley, or oats). At enrollment, the mean age of the patients was 5 months (range 1.5–15 months). By this time, 28 patients had been given small amounts of cow's milk-based adapted infant formula and 12 had ingested cereals. Altogether 35 (43%) patients suffered additionally from vomiting or diarrhea; none had respiratory symptoms. Atopy in first-degree relatives was found in 70 (86%) patients.

The mean total IgE was 41 kU/l (range 0–574 kU/l). Cow's milk allergy was diagnosed by double-blind placebo-controlled cow's milk challenge in 44 of 78 (56%) patients. Table 1 shows the results of specific IgE and SPT examinations. Serum-specific IgE antibodies were detectable and SPTs reactive to more than one food in 27% and 26% of patients, respectively.

Before entering the study, 42% of the mothers had eliminated specific food antigens (such as citrus fruits), 23% had eliminated cow's milk in addition, and 22% cow's milk and cereals in addition, from their diet during lactation to diminish the severity of their infant's atopic eczema. Only 13% of mothers did not modify their diet at any time during lactation. The

Table 1. The percentage of patients (n=81) with positive specific immunoglobulin E (IgE), skin prick test (SPT) examinations for dietary antigens, and double-blind placebo-controlled cow's milk challenge

Specific IgE positive (≥ 0.4 kU/l)	
Cow's milk	31%
Egg	27%
Wheat	17%
SPT positive	
Cow's milk	30%
Egg	26%
Wheat	19%
Cow's milk challenge positive	56%

mothers' general perception was that the more extreme the elimination diet was, the more beneficial it was to the infant, even if too demanding for the mother. The mean duration of exclusive breast-feeding was 3.4 months (0.1–7 months) and that of total breast-feeding 5.6 months (0.7–12 months). Most mothers decided to stop breast-feeding because the allergic symptoms in the infant continued irrespective of the maternal elimination diet.

At inclusion, the mean (95% CI) SCORAD score reflecting the extent, the intensity, and subjective symptoms of atopic eczema was 19.3 (15.8–22.8). After cessation of breast-feeding, the SCORAD score decreased to 8.2 (5.5–11.0);

$F=57.6$, $p < 0.0001$. During the intervention, the SCORAD score continued to decrease, being 4.3 (3.0–5.7) at the final study visit.

Problems in the management of an atopic infant

Before entering the study, 88% of parents had found the care of an atopic infant more demanding than that of a healthy child. Altogether 23 families had one or more healthy siblings. The parents with only atopic children reached their conclusion by comparing their experience with that of their friends and relatives with healthy children. Severe atopic eczema, pruritus, restlessness, sleep loss, difficulties in skin treatment, and adherence to a strict diet were perceived as the most important problems.

Half of the parents (53%) had consulted a general practitioner and the remainder had consulted a nurse at the well baby clinics for advice and help. The advice included follow-up (in 16% of cases) and topical treatment of the skin (29%), which the parents considered inadequate for the care of an atopic infant, whereas elimination of specific food antigens from the diet of the lactating mother (32%) and diagnostic evaluation (17%) were felt to be necessary. The remaining 6%

Table 2. The percentage of parents (n=81) grading the concerns in the care of an allergic infant as: non-existent, slight, moderate or severe, before entering the study (before) and after intervention (after)

Problem	Non-existent	Slight	Moderate	Severe	Statistics
Skin treatment					
Before	5%	21%	38%	36%	$\chi^2 = 34.3$ p < 0.0001
After	18%	43%	30%	9%	
Elimination diet					
Before	11%	20%	31%	38%	$\chi^2 = 16.7$ p = 0.05
After	7%	28%	41%	24%	
Diarrhea					
Before	43%	33%	17%	7%	$\chi^2 = 30.2$ p < 0.0001
After	56%	24%	20%	0%	
Vomiting					
Before	40%	24%	18%	18%	$\chi^2 = 49.1$ p < 0.0001
After	65%	22%	9%	4%	
Abdominal pain					
Before	26%	36%	24%	14%	$\chi^2 = 39.1$ p < 0.0001
After	58%	24%	14%	4%	
Restlessness					
Before	24%	25%	27%	24%	$\chi^2 = 28.5$ p = 0.0008
After	40%	26%	25%	9%	
Pruritus					
Before	19%	30%	26%	25%	$\chi^2 = 46.0$ p < 0.0001
After	32%	30%	26%	12%	
Sleep loss					
Before	28%	18%	24%	30%	$\chi^2 = 53.8$ p < 0.0001
After	30%	31%	23%	16%	
Parents' fatigue					
Before	14%	36%	29%	21%	$\chi^2 = 62.0$ p < 0.0001
After	12%	44%	30%	14%	

χ^2 , chi-square analysis.

had received no advice on the treatment of their atopic infant.

After intervention, 92% of parents again considered the care of an atopic infant more demanding than that of a healthy child, although all problems in the management of the infant had significantly diminished (Table 2). The main inconvenience was seen to arise from adherence to a strict dietary regimen, followed by skin treatment, pruritus, and sleep loss. Noticeably, severe concerns regarding an elimination diet decreased, but slight and moderate concerns increased during the study period.

Expectations from diagnostic and therapeutic intervention

With regard to diagnostic and therapeutic intervention the parents expected, in order of importance: alleviation of the symptoms experienced by the infant; practical advice on skin treatment and on elimination diets; accurate diagnosis of specific food allergies; and follow-up of nutritional state. The parents wished the pediatric nurse to be a link between parents and the doctor, to be available in the event of any problems (major or minor), and to support the families. From the pediatricians they expected time for care, consultation, and explicit instructions on treatment.

The perceptions of the family regarding the intervention

Altogether 92% of parents considered the help and advice they had received from the intervention team to be sufficient in the care of their atopic infant. They were satisfied with the holistic approach that the team had adopted in dealing with the atopic infants and their families. The expectations with regard to alleviation of symptoms were moderately or well fulfilled in 98% of cases, advice on skin treatment and elimination diet in 100%, allergy diagnosis in 94%, and follow-up of growth and nutrition in 100% of cases. There was a significant correlation between alleviation of symptoms and satisfaction with the intervention. The parents criticized the busy schedule of the pediatricians, the dermatologist, and the dietician, and also hoped for improvement in the exchange of information between them. They appreciated the individual doctor-patient relationship, the permanence of the medical staff, continuous follow-up, and the child- and family-centred care provided by the pediatric nurse.

Discussion

To our knowledge, this is the first study describing the concerns of parents with an atopic infant. Our results demonstrate that 90% of parents feel that the care of an atopic infant is more troublesome than that of a healthy child. The most important problems were severe atopic eczema and its treatment, pruritus, restlessness and sleep loss, and adherence to a strict dietary regimen. These problems may result in difficulties in the management of the infant and the allergy, which often exhausts the parents. Our results are consistent with those of previous studies in children with eczema, demonstrating chronic sleep disruption (15) and intensive scratching, which dominate family life (16). Although not investigated, it is probable that understanding the concerns of parents is a basis for improving the care and support of atopic infants and their parents.

Our data seem to support a comprehensive team approach for the care of an atopic infant. The results of the present study highlight that the problems in the management of the infant are significantly reduced during intervention, and the parents considered care provided by the team to be sufficient. This may be owing to the objective of the team: early detection and treatment of food allergies. A control group with no dietary intervention or no advice or treatment would have been helpful in distinguishing the effect of dietary intervention, topical treatment, and maturation on symptoms, but was considered unethical in the light of present knowledge on atopic eczema and food allergy. Consistent with the opinions of the parents, topical treatment of the skin and follow-up do not suffice as management for an atopic infant. Instead, the parents considered diagnostic evaluation to be of value, which is an essential basis for the elimination of suspected foods from the diet of the infant or the lactating mother. Only an elimination diet based on a proven food allergy benefits the atopic child, whereas an empirical elimination diet has no effect on atopic eczema (17). It is also an ethical issue that treatment which is as demanding as dietary modification is recommended only if substantiated by evidence. Accordingly, the opinions of the parents are also medically valid and consistent with evidence-based treatment.

Even exclusively breast-fed infants may become sensitized to dietary antigens present in breast milk (10, 18). We have recently demonstrated that if control of symptoms cannot be achieved by elimination of particular foods from the diet of the lactating mother, weaning to a tolerated hypo-allergenic formula

may be beneficial (10). It has previously been demonstrated that infants with early sensitization are at high risk of aeroallergen sensitization at the age of 5 years (19). Health care professionals should therefore target these children specifically and initiate diagnostic process and treatment of an atopic disease early in infancy. Simultaneously, attention should be paid to the many concerns of the parents.

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