

Agreement between parental reports and patient records in food allergies among infants and young children in Finland

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Abstract

Rationale, aims and objectives A third of parents suspect food allergy in their children. Questionnaire-based studies usually overestimate the occurrence of food allergies. The aim of the present study was to validate a study questionnaire by comparing children's use of special diets as reported by parents with patient records at the hospital.

Methods A population-based cohort with genetic susceptibility to type 1 diabetes (15% of those screened) was recruited in the Tampere area between 1997 and 2001, and followed for development of food allergy for 3 years. Food allergies and other special diets were queried at the age of 3 years with a structured questionnaire. The hospital records of the children, whose parents had reported an elimination diet of the child, were studied to validate the parental reports of food allergies. The hospital database was also checked for the respective diagnosis codes to estimate underreporting.

Results Altogether, 1122 parents returned the questionnaire at the study center visit when the child was 3 years old. Food allergy was reported by 15.0% of the parents. In 10.6% of the children food allergy had been diagnosed or confirmed at the hospital. Hospital-confirmed food allergy was unreported in 0.9% of the cases. The measure of agreement between reported and hospital-confirmed food allergies, using crosstabulation with Cohen's Kappa, was within 0.71–0.88 for cow's milk allergy, 0.74–0.82 for cereal allergy and 0.66–0.86 for any reported food allergy.

Conclusion We found that the validity of the questionnaire obtaining information on food allergies of infants and young children was good to excellent based on a comparison between parental reports and information obtained from patient records.

Introduction

Food allergies are often surveyed by questionnaires developed for the purposes of each study, and validation of the self- or parental-reported answers may be lacking. Questionnaires are likely to overestimate the occurrence of food allergy [1]. The reported prevalence and incidence of food allergy may differ not only because methods used in the studies differ, but also because the

occurrence of food allergies differs between countries [2] and age groups [3]. The parents report food allergy in 4.5% to 35% of infants and young children in different studies [4–10]. In Finland, parents suspect up to 30% of children aged 0–5 years to have food-related symptoms, and about 10% of the children have followed a therapeutic diet during the first 5 years of life [11].

Parentally perceived adverse reactions to foods have been confirmed in 1/15–1/3 of the children in different studies [6,9,12–14].

There are indications that not all adverse reactions to milk, which is the most rigorously studied and diagnosed food allergy, are recognized [12,15]. Thus, in questionnaires, food allergies are most often over- but on occasion underestimated. Questionnaire design in itself is a challenge [16], underlining the need for validation of each questionnaire.

The present study belongs to the longitudinal Type 1 Diabetes Prediction and Prevention (DIPP) Nutrition study, which assesses the role of dietary factors during pregnancy, lactation and early childhood on the development of preclinical and clinical type 1 diabetes, allergic diseases and asthma. The purpose of the present study was to validate the study questionnaire regarding special diets of children by comparing parentally reported food allergies to information from patient records.

Subjects and methods

Research design and subjects

The DIPP Study is a multidisciplinary prospective population-based cohort study [17]. All newborn infants from the catchment areas of three university hospitals in Finland (Turku, Oulu and Tampere) are screened for HLA-conferred susceptibility to type 1 diabetes from cord blood samples after parental informed consent. Infants who carry HLA (human leukocyte antigen) genotypes conferring high and moderate risk for type 1 diabetes (15% of those screened) are invited to participate in the study, excluding children with severe congenital abnormalities or diseases, or whose parents are of non-Caucasian origin or do not understand Finnish, Swedish or English. The DIPP Nutrition study is performed in the framework of the Oulu and Tampere sections of the DIPP Study population. In Oulu, the genetic screening and recruitment to follow-up of the newborns carrying increased susceptibility to type 1 diabetes started in 1995 and in Tampere in 1997; the screening and recruitment continue. The children in the DIPP Nutrition study, born between October 1997 and June 2001 in the Tampere area ($n = 2125$), were selected for the present study. The local Ethical Committee approved the study. All families have given their written informed consent.

Validation of the questionnaire

Food allergies and other special diets were queried at the age of 3 years with a structured questionnaire. Questions were as follows: has the child ever had cow's milk allergy (CMA), allergy to wheat, barley, rye and/or oats (cereal allergy, CEA), other food allergies; have commonly allergenic foods been avoided in the child's diet; use of vegetarian diets and other special diets. There were also questions for each of the diets about the person on whose initiative the diet had been started (parents or health care professional) and about the age of the child when the diet started and ended.

The patient records of the children attending the DIPP-study clinic in Tampere University Hospital, and who had an elimination diet reported in the study questionnaire, were reviewed to validate the parental-reported responses of elimination diets. In Finland, the majority of children with suspected CMA, CEA or celiac disease are examined at the Departments of Pediatrics and/or Dermatology in the hospital responsible for the health care in the area, where the family lives. Therefore, children with any special diet

reported were included in order to study possible misreporting of food allergies as other special diets. The hospital database was searched to identify children in the study with an unreported diagnosis of food allergy by using international classification of diseases (ICD-10) codes L27.2 and K52.2. The patient records of all participants assigned with either of the codes were reviewed.

Data handling and statistical methods

All information from the questionnaires was double-entered into a database. In addition, 10% of all questionnaires were checked again to ensure valid pre-coding and recording of the answers. SPSS 12.0.1 software package (SPSS, Chicago, IL, USA) was used for data handling and statistical analyses. Reported special diets were classified into allergic and non-allergic categories, where avoidance of commonly allergenic foods was not considered to be due to diagnosed allergy. Crosstabulation with Cohen's Kappa was used to measure the agreement between reported and diagnosed food allergies. Statistical tests were calculated for two scenarios: (1) none of the children with insufficient information from the patient records were diagnosed with food allergy; and (2) all of the children with insufficient information from the patient records were diagnosed with food allergy.

Results

Parental reports on food allergies

Altogether, 1122 3-year questionnaires were returned by the parents. Of those originally invited to take part in the DIPP Study, 53% participated in the Nutrition Study at the age of 3 years in this study population. Of the children 52.8% were boys and 47.2% girls. Any food allergy was reported by the parents of 168 children (15.0% of all), and any special diet by 241 (21.5% of all) (Table 1). CMA in the child was reported by 9.2% of the parents, with 83.5% reporting that the elimination diet had been initiated by a health professional. CEA in the child was reported by 8.1% of the parents, with 86.8% reporting that the elimination diet had been initiated by a health professional. Egg allergy was reported by 4.8% and fish allergy by 2.6% of the parents.

Validation against patient records

Altogether, 263 children fulfilled the criteria of either parentally reported special diet ($n = 241$) or diet not reported, but having a diagnosis code at the hospital database ($n = 22$), and were included in the patient records reviewed. Out of the 263 children, 118 had visited the hospital because of food allergies. In addition, 50 children had visited the hospital for reasons other than food allergy, and for 28 of them patient records showed reasonable proof of food allergy diagnosed elsewhere, such as a doctor's certificate. The hospital database revealed the additional 22 children with a diagnosis code indicating a probable food allergy diagnosis; 10 of these did have food allergy diagnosed at the hospital. Thus, food allergies were unreported by 0.9% in this cohort (10 out of 1122).

According to the patient records, 119 (10.6%) children had been diagnosed with food allergy by the age of 3 years. Of the 168

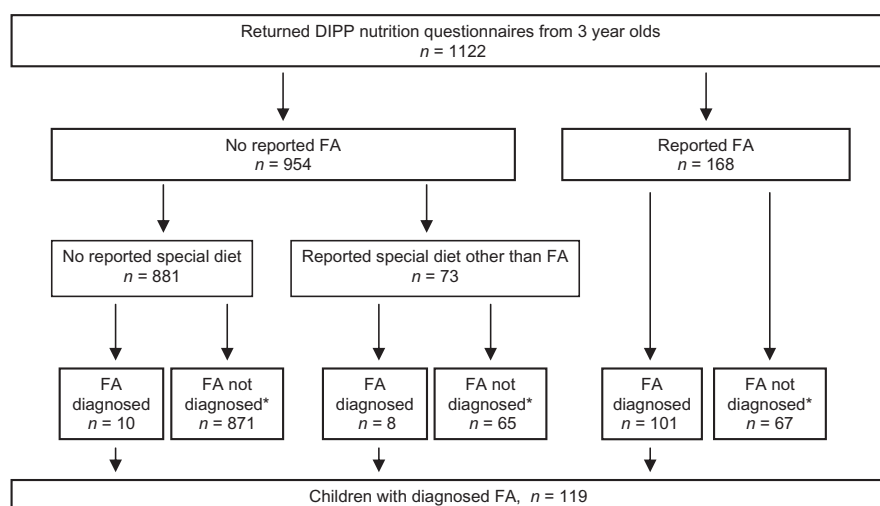
Table 1 The number of special diets in children by the age of 3 years in a cohort of 1122 children, as reported by the parents in a self-administered questionnaire

Special diet or a disease requiring a special diet	All (n)	Initiated by a health professional (n)	Initiated by family (n)
Cow's milk allergy	103	86	6
Lactose intolerance	34	14	19
Allergy to wheat, barley, rye and/or oats	91	79	4
Celiac disease	8	4	2
Any food allergy	168	126	22
Avoidance of commonly allergenic foods	118	99	9
Any special diet*	241	163	59

The number of diets recommended by a health professional or initiated by the family is also shown. Not everyone reported of whose initiative the diet was started.

*Other special diets include diets related to various diseases, as well as diets because of ethical or religious reasons.

Figure 1 Reported and diagnosed food allergies (FA). *No indication of food allergy in patient records at the hospital.



children reported to have food allergy, 101 (60.1%) had received the diagnosis at the hospital (Fig. 1). Eight of the 73 children reported to having been on a special diet because of other reasons (other reasons being lactose intolerance, celiac disease, avoidance of commonly allergenic foods, or special diet not specified) actually had a diagnosis of food allergy.

Of those 168, who had a food allergy reported, 46 (27.5%) had not visited the hospital at all. They had either been diagnosed in primary health care or by private practitioners, or their food allergy had not been diagnosed by a doctor. For them, the patient record data were insufficient to conclude whether the child had been diagnosed with food allergy or not. Cohen's Kappa between reported and diagnosed allergies, calculated as worst case and best case scenarios as regards to the insufficient data, were within a range of 0.71–0.88 for CMA, 0.74–0.82 for CEA and 0.66–0.86 for any reported food allergy ($P < 0.001$ for all). CMA was diagnosed in the hospital in 6.3% of the study children, and the diagnosis was confirmed in hospital records in 62% of the children whose parents had reported it (Fig. 2). For CEA, the numbers were 6.8% and 69%, respectively (Fig. 3).

Of the 71 children diagnosed in the hospital with CMA, 41 (57.7%) had had a positive oral challenge test, and of the 76 children diagnosed with CEA, 22 (28.9%) had had a positive oral challenge test to confirm the diagnosis. The diagnosis of the

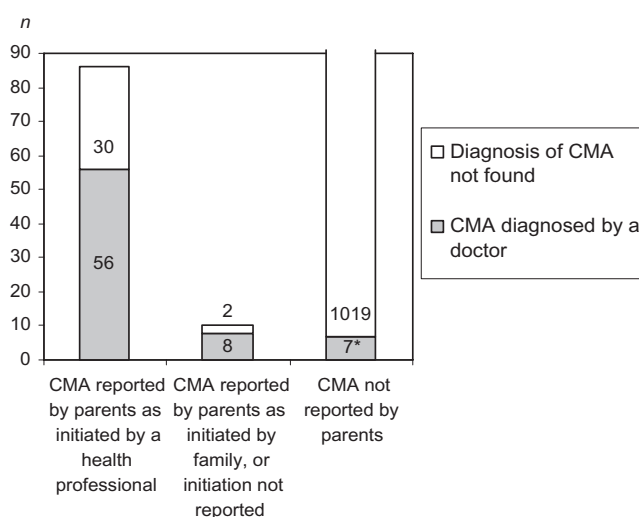


Figure 2 Cow's milk allergy (CMA) as reported by parents, and whether a diagnosis was found from patient records. *Those who had not reported CMA had reported either some other special diet or had a diagnosis code (international classification of diseases, ICD-10 codes L27.2 and K52.2) indicating food allergy diagnosis at the hospital database records.

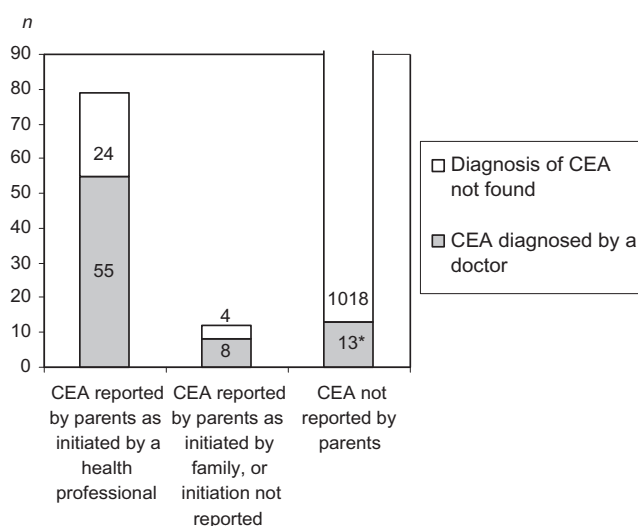


Figure 3 Allergy to wheat, barley, rye and/or oats (cereal allergy, CEA) as reported by parents, and whether a diagnosis was found from patient records. *Those who had not reported CEA had reported either some other special diet or had a diagnosis code (international classification of diseases, ICD-10 codes L27.2 and K52.2) indicating food allergy diagnosis at the hospital database records.

remaining cases had been based on a combination of suggestive history and skin prick tests, analyses of serum specific IgE, or patch tests. The cumulative incidence of CMA and CEA, if only children with a documented positive oral challenge test are accepted as having a firm diagnosis, is 3.7% and 2.0% in this cohort, respectively. By the age of 3 years, none of the children had received the diagnosis of celiac disease.

Discussion

Patient record data regarding food allergies of the infants and young children correlated well with the information provided by the parents in the questionnaire. In our cohort of 1122 children, one in five children was reported to have been on a special diet by the age of 3 years and about one in seven had followed a special diet because of food allergy. According to patient records, at least one in 10 children had been diagnosed with food allergy.

The response rate at the age of 3 years was 53% of those initially invited to the study. However, not all 47% were lost to follow-up; some have merely skipped filling the questionnaire at this age point and may well return the questionnaire at a later age. Participants of the DIPP Study in Tampere region are invited to participate in the DIPP Nutrition Study, and questionnaires for the nutrition study may be filled at the child's ages of 3 and 6 months, 1 year and annually thereafter. Of those who had returned a questionnaire at the age of 3 months, 66% returned a questionnaire at the age of 3 years. According to the diagnosis codes of the hospital database, fewer children who did not participate at the age of 3 years had visited the hospital for allergy-related reasons than those who took part in the study at this age point (data not shown). The diagnosis database of the hospital does not provide solid

information about the diagnosis of food allergy, but it can be regarded as a rough indicator of food allergy-related examinations at the hospital.

In the present study, food allergies of children were queried retrospectively at the age of 3 years. Because most children with CMA or CEA have become tolerant by that age, it was not possible to confirm these allergies by an oral challenge in this study. We therefore decided to rely on the expertise of pediatricians and allergologists responsible for the diagnosis and treatment of food allergy, although practices for diagnosis of food allergy vary to some extent [18]. However, the primary aim of the present study was to validate the questionnaire against the patient records, not to validate the diagnostic practices.

Food allergy is an adverse immunologic reaction resulting from ingestion of a food. Food allergy disorders include gastrointestinal, cutaneous, respiratory and generalized symptoms. Diagnosing food allergy is a challenging task. All the symptoms of food allergy may also be caused by other allergens or mechanisms, and there is no single test that unequivocally indicates whether a child is allergic to a certain food or not [19]. Food allergy is optimally diagnosed with double-blind placebo-controlled oral challenge [20]. However, it is a rather laborious and time-consuming procedure, and therefore an open challenge is used in clinical practice [21]. Thus, the diagnosis of food allergy is based on medical history, skin prick tests, serum specific IgE, and a positive response to a diagnostic elimination diet and an oral challenge.

Our method of validation, measuring parents' answers in the questionnaire against children's patient records, is dependant on the accuracy of food allergy diagnosis and in how much detail it is documented in the patient records. Interpreting whether an elimination diet is diagnostic or therapeutic is not always unambiguous. The children's patient record data were collected without knowing the questionnaire responses, and by one person (JT). Meanwhile, parents report food allergy in the questionnaires according to what they have heard and understood during their visits at the hospital or other sites of health care. The communication skills of both parties, as well as the parents' decision to either follow or disregard the given instructions, may further enhance the uncertainty of the validation.

A limitation of the study is that data from patient records were not available from the private practitioners. Data were also not collected from primary health care. The latter is primarily responsible for diagnosing and treating children with food allergies other than CMA or CEA. About one in four of the children, whose parents reported that the child had had food allergy, had not visited the hospital. They had either been diagnosed in primary health care or at private clinics, or the child did not have a food allergy diagnosed by a doctor. Because of these incomplete data, we were unable to properly analyze the extent of over-reporting. Validation of food allergies other than CMA and CEA is suggestive only. All in all, food allergies other than CMA and CEA are not diagnosed as rigorously, as they are not nutritionally as significant.

There may have been misunderstanding of questions in our study questionnaire – because of the questionnaire, or just as well because of the sometimes ambiguous nature of the whole process of diagnosis. There were reports that the child's diet was started by the family, although patient records revealed that the food allergy had been diagnosed by a doctor. Most likely such diets were originally initiated by the family and later confirmed by the doctor.

In some cases, short-lasting diagnostic elimination diets seem to have been reported as food allergy (seven and six children with reported CMA and CEA, respectively).

As many as 11 of 14 (79%) children with diagnosed fish allergy reported avoidance of commonly allergenic foods, and only six of 14 (43%) reported fish allergy. Likewise, 38 of 48 (79%) of children with a diagnosed allergy to egg reported avoidance of commonly allergenic foods, and only 23 of 48 (48%) reported egg allergy. Therefore, this questionnaire underestimates the occurrence of egg and fish allergies. Data about egg and fish allergy diagnosis are only available for those with CMA or CEA, or suspicions thereof.

None of the eight children reported to have celiac disease had been diagnosed with the disease at the Pediatric Clinic by the age of 3 years. These children probably had CEA, although only two of them had received this diagnosis at the hospital.

Food allergy was not reported in 0.9% of the children who actually had the diagnosis in the hospital records by the age of 3 years. An open-ended question was posed at the ages of 3 and 6 months, and 1 and 2 years, and apparently some parents did not repeat their previous answers. Of seven unreported CMAs, six had been previously reported, and of 13 unreported CEAs, five had been reported in a previous questionnaire, two had reported celiac disease and one unspecified multiple allergies.

A disadvantage of this study is the HLA-conferred susceptibility to type I diabetes of our study population. Some studies have found an inverse association between type 1 diabetes and some forms of atopic diseases [22,23], while others suggest a positive association between allergy and diabetes [24]. There is no definite knowledge about the possible effect of genetic susceptibility to type I diabetes on the risk of allergic diseases, including food allergy. As regards to food allergy and other forms of atopic diseases, this cohort of children is an unselected one. Because the DIPP study primarily focuses on pre-clinical and clinical type 1 diabetes and not atopic diseases, the risk of response bias is actually diminished [25], which is in fact a major strength of the study.

In conclusion, parents of Finnish infants and young children report their children's food allergies concordantly with patient records. Two-thirds of the parentally reported food allergies had been diagnosed by a doctor. In this cohort of infants and young children, the correlation between questionnaire-reported food allergies and information collected from the patient records was good to excellent.

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