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Original article

Assessment of dietary compliance in celiac children using a standardized dietary interview

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SUMMARY

Background & aims: Compliance to a gluten free diet (GFD) in celiac disease (CD) is ideally assessed by dietary interviews, albeit time-consuming. Short dietary questionnaires have been developed for adults but not for children. Primary aim was to compare GFD compliance in celiac children, measured by a short dietary questionnaire against a dietary interview. Secondary aims were correlation between both questionnaires and celiac antibodies and identifying variables predicting noncompliance.

Methods: Between 2012 and 2014, participants in the E-health CoelKids study, completed a short dietary questionnaire and standardized dietary interview together with measurement of anti-tissue transglutaminase antibodies (TG2A). Results of the questionnaires were assigned under similar categories. Factors possibly influencing dietary compliance were recorded. Where appropriate, Pearson's Chi-square test for trend, unpaired t-test, Cohen's kappa and one-way ANOVA were used.

Results: 151 of 165 participating patients were studied, 66% were female. Mean age was 11.3 years (2–26, SD 5.4), mean age at CD diagnosis was 4.9 years (1–23, SD 4.0). The short questionnaire and dietary interview correlated poorly, detecting problems in dietary adherence in 14% and 52% of the patients, respectively (Cohen's kappa 0.034). Only the short questionnaire correlated with TG2A (p = 0.003). Only older age was associated with noncompliance, the mean age of completely nonadherent, adherent but committing errors, and strictly adherent patients were 15.5, 11.5 and 10.1 years, respectively (p < 0.001). *Conclusions:* Compared to the dietary interview, short dietary questionnaires and TG2A serology failed to detect dietary transgressions in CD children, wherein adolescents were shown to be at highest risk.

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1. Introduction

Celiac disease (CD) is an immune-mediated systemic disorder elicited by gluten in genetically susceptible individuals and is characterized by anti-tissue transglutaminase type 2 antibodies (TG2A) and enteropathy [1]. In individuals carrying the HLA-DQ2 and/or DQ8 haplotype, the ingestion of gluten (a group of proteins present in cereals such as wheat, barley and rye, can lead to a T cell-initiated inflammatory response, damaging the small bowel mucosa [2]. CD is a common disorder, occurring in approximately 1–3% of the general population [3,4]. The disease has a variable

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clinical presentation, ranging from malabsorption with diarrhea, abdominal distention and weight loss, to nonspecific signs and symptoms such as fatigue, osteoporosis or iron deficiency anemia. CD can be diagnosed by the detection of CD-specific antibodies (usually IgA class tissue transglutaminase antibodies TG2A and anti-endomysium antibodies) [5,6] and small bowel biopsies that show characteristic histological alterations. CD can be successfully treated in most cases with a gluten free diet (GFD) which restores small bowel histology and improves symptoms. However, this diet may be difficult to follow and may lead to social constraints. It is known that dietary adherence differs among individuals, with noncompliance varying from 25 to 50% [7–9] among children and adolescents. Despite the absence of a gold standard to assess dietary compliance [10], a dietary evaluation by a trained dietitian is considered the best method [11]. Repeat duodenal biopsies to monitor mucosal recovery is usually not a practical option,

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especially in children wherein endoscopy to obtain biopsies is done under anesthesia or deep sedation. Serologic testing is not sensitive enough to detect infrequent gluten exposure [12–14]. It has been shown that adults tend to overestimate their level of compliance if they are asked to self-report it [15]. Furthermore, information about the trustworthiness of adherence as reported by parents show a broad range [16]. Food diaries and questionnaires are frequently used in CD research in order to estimated gluten intake. These are, however, mostly used in order to assess the diet's nutritional content [17,18] and have not been validated, except for food questionnaires in infants [19] and children aged 1-4 years [20]. A dietary interview to assess compliance is time-consuming, taking 20-30 min per patient, and requires expert personnel. Several short questionnaires have been developed to measure GFD adherence in order to save time and address compliance in a standardized manner. For example, a questionnaire developed in Italy and tested in celiac adults [13] consists of four questions that take less than a minute to administer. Moreover, it may be filled out even by non-expert personnel or by patients themselves online. To our knowledge, these short questionnaires have never been tested in children, adolescents or young adults.

The primary aim of this study was to compare GFD compliance in CD children, adolescents and young adults as measured by a short and standardized dietary questionnaire that has been validated in celiac adults [13] against a standardized dietary interview. Secondary aims include 1. the assessment of the correlation between the short dietary questionnaire, standardized dietary interview and celiac-specific serum antibodies, and, 2. the identification of risk factors for noncompliance with the gluten free diet.

2. Materials and methods

For this cross-sectional study, dietary compliance was assessed in celiac children and young adults participating in the E-health CoelKids study and who were randomized to receive the usual health care (www.coelkids.nl). Patients were recruited between May 2012 and July 2014. They became eligible if CD was diagnosed according to ESPGHAN criteria [1,21] at least 1 year before enrolment and patients (or their parents) could complete the online questionnaires in Dutch. As part of the CoelKids project, the patients and/or parents were asked to complete two questionnaires about dietary compliance. The first questionnaire consisted of a Dutch adaptation of a short questionnaire validated in Italian CD adults to assess GFD compliance, hereafter referred to as the "short questionnaire" [13] (Fig. 1) in this article.

The scores obtained from this questionnaire were divided into three scores: 1 - indicating GFD not followed, 2 - GFD with important errors, 3 - strict GFD. The second questionnaire, hereafter referred to as the "dietary interview questionnaire", consisted of an extensively written patient interview developed by one of the authors (EH) who is an experienced dietitian specializing in CD and GFD. This 26-item questionnaire reflects the patient interview that was verbally conducted during regular face-to-face consultations with the dietitian to evaluate the GFD (Supplemental material, Annex A). This interview was standardized and converted into a written version for this project. It addresses several domains, including GFD compliance and patient (or parent) knowledge and attitude toward the GFD. For example, they were asked about gluten-free food preparation, the reading of food labels, and the need for extra information/contact with a dietitian or medical doctor. For optimal comparison, the final scores of the dietary interview questionnaire were grouped into the same three scores obtained from the short questionnaire. In addition, to improve user-friendliness, a comprehensive 11-item version of the dietary interview was also tested (Supplemental material, Annex B).

The questionnaires were completed after a regular patient (and parent) outpatient visit for CD follow up. The questionnaires were filled out by the parents if the child was younger than 12 years or by the parents and child together if the child was older than 12. Since the visit was a regular medical check for CD, celiac-specific antibodies in the serum were tested according to (inter-)national CD guidelines [22,23]. The Coelkids study protocol was approved by the Medical Ethical Committee of LUMC and by the respective boards of each participating center and complied with Good

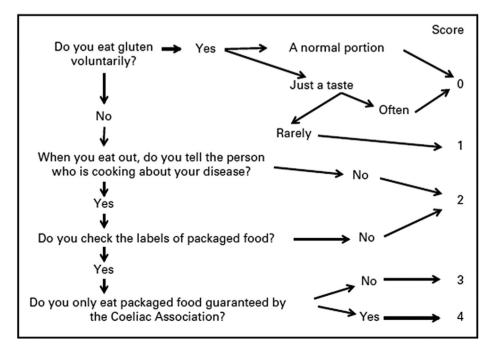


Fig. 1. Short diet questionnaire validated in celiac adults [13]. 'Often': the patient consumes gluten quite frequently that he/she cannot remember when and how many times that has happened. 'Rarely': the patient consumes gluten only occasionally. She/he can remember when and how many times that has happened.

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