

# Management of coeliac disease patients after the confirmation of diagnosis in Central Europe

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**Background** Recently published paediatric guidelines for diagnosing coeliac disease do not include recommendations on the follow-up of coeliac disease patients.

**Goal** The aim of this study was to assess the management practices and experience of coeliac disease patients with their follow-up appointments in Central Europe.

**Study** Gastroenterologists and coeliac disease patients in five Central European countries were asked to complete the web-based questionnaire focusing on coeliac disease management practices.

**Results** Answers from 147 gastroenterologists and 2041 coeliac disease patients were available for the analysis. More than half of the gastroenterologists (58.5%) schedule the first follow-up visit within 3 months after the diagnosis. At follow-up, tissue transglutaminase antibodies are checked in almost all patients (95.9%). Approximately two-thirds (60.7%) of gastroenterologists refer all of their patients to the dietitian at diagnosis. Similarly, 42.8% of coeliac disease patients reported that they had not been appointed to a dietitian. Almost one-third of coeliac disease patients (30.8%) reported that they had no follow-up appointments with gastroenterologist at all.

**Conclusions** Follow-up of coeliac disease patients is suboptimal in Central Europe. Many patients are not followed regularly. A lot of patients are not referred to a dietitian. The recommendations on the optimal follow-up of coeliac disease patients are needed in order to improve patient care. *Eur J Gastroenterol Hepatol* 34: 27–32  
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## Introduction

Coeliac disease is one of the most common lifelong systemic autoimmune disorders, elicited by gluten and related prolamines in genetically susceptible individuals [1]. It has a very diverse clinical presentation and is associated with a number of other conditions, including type-1 diabetes, IgA deficiency, autoimmune thyroid disease and certain chromosomal abnormalities such as Down

syndrome, Turner syndrome and Williams syndrome [1–4]. The first diagnostic criteria for the coeliac disease were the Interlaken criteria, formalized in 1969 by the experts in the newly established European Society for Paediatric Gastroenterology, today known as European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN). These criteria were regularly revised by ESPGHAN, and this year, a new version of revised guidelines for diagnosing coeliac disease has been published [1]. Although during the decades many improvements were proposed regarding the diagnostic procedure, none of the previously existing ESPGHAN guidelines nor current ESPGHAN guidelines include the recommendation on how to follow coeliac disease patients after the diagnosis is confirmed. In several other guidelines, some recommendations on when the follow-up should be carried out or what investigations should be performed are included; however, these recommendations are mostly not evidence-based [5–11].

Regular follow-up is very important in order to assess the improvement of the disease, compliance with the strict gluten-free diet, quality of life of coeliac disease patients and their coping with the disease in everyday life. Also, follow-up serves to prevent disease complications and to identify possible autoimmune comorbidities [5,12–15].

As it has been already stated, there is not much data on how to follow coeliac disease patients, including the frequency of follow-up visits and planned investigations. Therefore, the aim of our study was to assess the existing

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management practices and experience of coeliac disease patients with their follow-up appointments in Central Europe.

## Methods

The study was carried out between April 2017 and October 2019, as a part of the Focus IN CD project (CE 111), co-financed by the EU Interreg CE Programme. Twelve partners from five Central European countries (Croatia, Germany, Hungary, Italy and Slovenia) participated in the project.

### Participants and study design

Two specific questionnaires (<https://www.interreg-central.eu/Content.Node/surveys.html>), focusing on coeliac disease management practices in Central Europe, were conducted and distributed by the project partners. Within the questionnaire designed for gastroenterologists working with coeliac disease patients, 20 questions were focusing on patient follow-up practices, whereas in the one designed for patients, 18 such questions were asked. Both questionnaires were translated into the languages of all project partners.

### Gastroenterologists

Gastroenterologists from five Central European countries ( $n=147$ ) were asked by the regional project partners to complete the web-based questionnaire about the management of their coeliac disease patients. Questions were focusing on the diagnostic procedure for coeliac disease, on the regularity of medical follow-up, on the regularity of dietary counselling and on investigations performed during the follow-up.

### Patients with coeliac disease

Patients with coeliac disease from the same five Central European countries ( $n=2041$ ) were asked about their experience with the follow-up. They were asked about the frequency of follow-up appointments and their experience and satisfaction with the disease management.

### Statistical analysis

Statistical analysis was performed using IBM SPSS Statistics 22.0 for Windows.

The study was approved by the National Medical Ethics Committee of the Republic of Slovenia (0120-383).

## Results

Answers from 147 gastroenterologists and 2041 coeliac disease patients (60.1% patients, 39.9% caregivers) from Croatia, Hungary, Germany, Italy and Slovenia were available for the analysis.

### Gastroenterologists

More than half of the gastroenterologists (58.5%) schedule the first follow-up visit within 3 months after the confirmation of the diagnosis and 98% within 6 months. In the majority of patients (58.3%), follow-up visit lasts 20–25 min.

At the follow-up visit, tissue transglutaminase antibodies are checked almost always (95.9%), followed by antiendomysial antibodies (37.4%). Among other laboratory parameters, complete blood count is always performed in 52.4% of patients (Fig. 1).

The frequency of further follow-up visits mostly depends on clinical presentation (85%) and laboratory tests (73.5%). If a patient is not reporting an improvement, the second follow-up visit is scheduled after a month in 18.5%, and in 78.8%, this visit is scheduled within 3 months. If at the first follow-up visit, patient is reporting an improvement, the second follow-up visit is scheduled after 6 or 12 months (41.4 and 34.5%, respectively), and when stable, once a year (88.8%). During adolescence, gastroenterologists usually (62.6%) do not increase the frequency of follow-up visits.

About 15% of participants declared not to have dietetic counselling available at their institution, with dietetic counselling paid fully or partially by their health insurance in the majority of cases (95%). At the confirmation of the diagnosis, only about two-thirds (60.7%) of gastroenterologists refer all of their patients to the dietitian and four never refer their patients to a dietitian, and 10% refer less than 50%. However, at follow-up visit, only 6% refer all of their patients and two-thirds of gastroenterologists refer less than half.

Paediatric coeliac disease patients are usually transferred to adult care at the age of 18 (81.9%). Mostly there is no formal transition (50.3%) or only a written transition report is provided (39.5%).

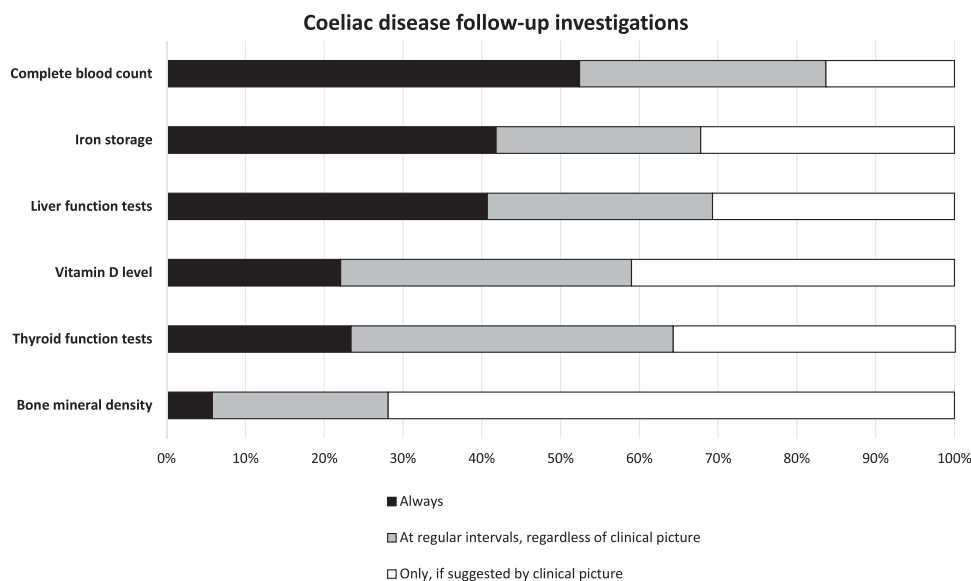
### Coeliac disease patients

The majority of included coeliac disease patients were members of national or local patient support groups (80.8%). Dividing paediatric ( $n=814$ ) and adult ( $n=1227$ ) coeliac disease patients, we found that 56.9% of paediatric coeliac disease patients had follow-up appointments at least once a year. Almost one-third (30.3%) reported that they did not have any follow-up appointments. The majority outlined that follow-up visits lasted 5–20 min (59.5%) and most of them (64.0%) were satisfied with the given time. However, one-third (33.3%) felt that the follow-up visit should last longer.

A similar situation was found in adult coeliac disease patients since 31.1% were not followed by the gastroenterologists at all and only 29.5% were followed at least once a year. Almost half (49.9%) reported that the appointments last 5–15 min; however, 56.4% of them felt that they should have more time for the follow-up visit.

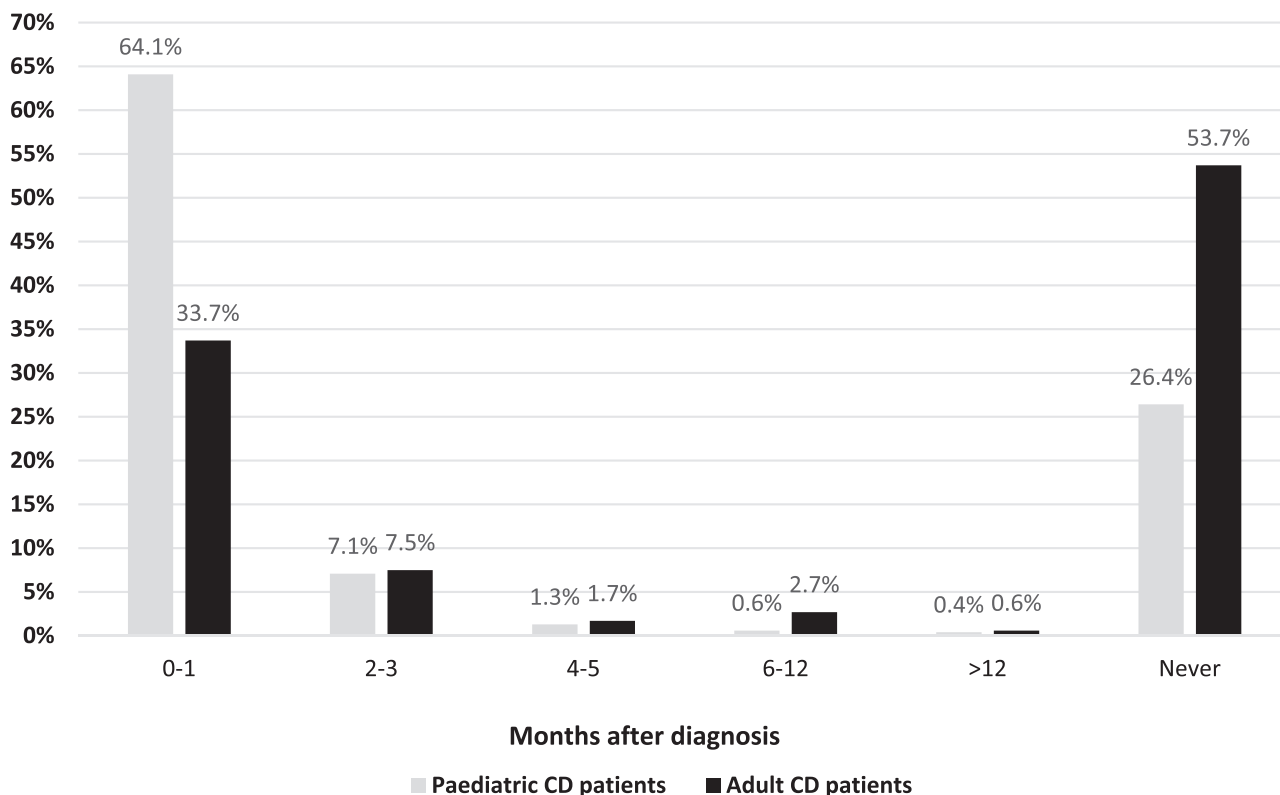
When asked, how often in their opinion should the follow-up visit be scheduled, 71.1% of paediatric patients that are followed at least once a year felt that the follow-up visits should be scheduled as it is and 23.8% felt that the visits should be scheduled more often. Adult patients that are followed at least once a year mostly (69.5%) responded that they are satisfied with one appointment per year and 18.1% felt that the visits should be scheduled more often.

Comparable with the data provided by gastroenterologists, 42.8% of coeliac disease patients reported that they had not been appointed to a dietitian. However, among paediatric coeliac disease patients, 73.6% were appointed to a dietitian, most of them within the first month after the diagnosis was confirmed (87.1%). On the other hand,



**Fig. 1.** Investigations, performed at the follow-up visits of coeliac disease patients.

## First dietetic counselling



**Fig. 2.** Time of the first dietetic counselling after confirmation of diagnosis as reported by patients.

less than half (46.3%) of adult patients visited dietitians, mainly in the first month after the diagnosis was confirmed (72.9%) (Fig. 2).

### Discussion

To date, there is not much available data on how the follow-up of newly diagnosed coeliac disease patients should be arranged. Despite the importance of regular follow-up,

some studies showed that many coeliac disease patients are not being followed regularly after the confirmation of the diagnosis [16,17]. In children, current ESPGHAN guidelines [1] contain no recommendation on follow-up; however, NASPGHAN and BSPGHAN guidelines, together with guidelines for the management of adult coeliac disease patients mostly propose to annually assess symptoms, growth, adherence to the gluten-free diet and some also advise to check markers of small intestinal absorption,

bone health and associated autoimmune conditions [5–10,13–15,18]. However, the set of investigations that should be done was studied recently, and it was proposed that follow-up should be problem-oriented, based on symptoms and signs rather than on routine screening of malabsorption parameters [19–21]. Complementary blood investigations, relevant at the time of diagnosis of coeliac disease, are suggested to have little diagnostic yield during follow-up visits once the patient is put on a gluten-free diet and routine laboratory screening in the absence of clinical problems seems to be unnecessary [20–22].

It has been suggested that paediatric and adult coeliac disease patients should be controlled by a multidisciplinary team each 3–6 months from diagnosis to stabilization. After substantial improvement has been obtained, annual evaluation is recommended [5–10,13–15,18,19,23]. In our study, in line with available data, gastroenterologists reported to follow newly diagnosed coeliac disease patients mostly up to 6 months after the confirmation of the diagnosis and on a yearly basis thereafter. However, we observed the discrepancy comparing the data provided by gastroenterologists and patients, with approximately one-third of patients reporting no follow-up after the diagnosis. Almost one-third of paediatric coeliac disease patients reported not being followed by paediatric gastroenterologist, which is more in comparison to the study of Blansky *et al.* [24], where 9% of children had no follow-up visit and in comparison to the study of Kurppa *et al.* [25], where 5% of children were not followed. It has been shown that paediatric patients that are lost to follow-up are more likely to be nonadherent to a gluten-free diet and more often have positive serology [26]. Regarding the adult coeliac disease patients, our results are comparable to the study of Cohen *et al.* [27], where 31% included adult patients had no follow-up visit and lower in comparison with the study of Kurppa *et al.* [25] where 69% of adult coeliac disease patients were not under any kind of follow-up for their disease.

The importance of visiting a dietitian was emphasized in many studies. Dietary counselling may serve as an instrument for improving patient adherence to gluten-free diet [27,28], even though some studies showed that lack of dietary counselling was not associated with dietary non-adherence [25,29]. However, it also serves as an important instrument to evaluate nutritional status, to optimize and nutritionally balance gluten-free diet [30] and to offer support to the families facing many challenges of newly changed dietary lifestyle [13,15,19,27,30–32]. Moreover, the study of Johansson *et al.* [33] showed that moving the follow-up of children with coeliac disease from mainly paediatric to dietitian visits was associated with similar levels of dietary compliance and may provide lower long-term costs.

However, not all coeliac disease patients are referred to a dietitian after the diagnosis is confirmed. This is supported by the data provided by gastroenterologists and coeliac disease patients, indicating that only two-thirds of patients are referred to a dietitian after the diagnosis is confirmed. This is lower compared to Blansky *et al.* [24], where 83% of participants consulted a dietitian. However, according to our results, on follow-up visits, referral to

the dietitian is even rarer. There are several possible reasons for low referral rate. Lower availability of dietitians in some regions may be one of the important factors; however, our results show that only a few centres do not have a dietetic service in their institution. Another, probably more important cause, could be a cost associated with dietetic counselling. However, our data show that dietetic counselling is, in the majority of cases, covered by insurance. A possible reason for this could also be the lack of clear guidelines on follow-up of coeliac disease patients where the role of a dietitian would be clearly defined.

It has been shown that teenage patients were likely not to be adherent to the gluten-free diet [25,26,29]; however, according to our data, the frequency of follow-up visits is not increased during adolescence.

At diagnosis, patients should be encouraged to join patient support groups, which can provide emotional and psychologic support and can serve as a source of information about gluten-free products and restaurants available locally [7,8,19]. Our results showed that this is encouraged by most of the gastroenterologists, and consequently, the majority of included coeliac disease patients reported to be members of patient support groups.

There is not much information on how the transition from paediatric to adult care should be arranged. It has been suggested that the physician starts a discussion about transition when the child is 12–13 years old, develops a transition plan at the age of 14–15, with the actual transfer taking place at  $\geq 18$  years of age [23,34]. The transfer is recommended to be structured and to include at least the minimum written information on the base of diagnosis, follow-up, anthropometric data, comorbidities and dietary compliance [23,35]. We found that transfer in Central Europe is usually arranged at the age of 18 years, but mostly without formal transition or only with transition report. This could be a potential reason for some patients being lost to follow-up and should be improved in order to prevent gaps in care. Studies have shown that receiving a referral for ongoing adult coeliac disease care was an important predictor of successful transition [35].

With the current COVID-19 epidemic, follow-up practices of coeliac disease patients had to change in many ways, mostly because of the lower accessibility of medical institutions due to epidemiological restrictions. In this regard, some telemedicine solutions to assess dietary adherence, patients' well-being and clinical status could be utilized involving both medical doctors and dietitians.

### **Strengths and limitations**

The results of our study provide an insight into the current follow-up practices from the gastroenterologists' and coeliac disease patients' perspectives in Central Europe. One of the limitations of the study is the inability to directly correlate patient data with their respective gastroenterologists because of the anonymous data collection. Also, the low number of participating adult gastroenterologists does not allow to compare paediatric and adult gastroenterologists' follow-up practices and to make regional comparisons. Possible limitation is also a relatively high proportion of patient support group members, which could be more aware of the disease and could therefore be

more active in seeking medical attention. Nevertheless, the very high number of participating coeliac disease patients represents the important strength of the study. Also, having similar questionnaires for both gastroenterologists and coeliac disease patients, providing answers during the period without any important changes in the coeliac disease-related guidelines enabled us to compare the answers between both groups.

To conclude, we found that the follow-up of coeliac disease patients in Central Europe is suboptimal. Many patients reported no follow-up visits despite different information coming from gastroenterologists. Also, a lot of patients did not have an appointment with the dietitian, which can affect the compliance to the diet and long-term outcomes of the disease. The guidelines on the proper follow-up of coeliac disease patients are needed to improve and harmonize patient care.

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### Conflicts of interest

There are no conflicts of interest.

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