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Uncovering the gap: Coeliac disease knowledge among healthcare professionals in the Danube region

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Abstract

Background Several studies have shown that the knowledge about coeliac disease (CD) is not satisfactory among healthcare professionals (HCP). The aim of our study was to assess the knowledge of HCPs about CD in the Danube region.

Methods HCPs from 8 countries in the Danube region were asked to complete the web-based questionnaire about CD. Scores of HCPs were compared according to their speciality, work experience and country of residence. The results were compared with the results of a similar study conducted in Central Europe within the Focus IN CD project in 2016.

Results Questionnaire was completed by 799 HCPs from Austria, Croatia, Czech Republic, Hungary, Moldova, Romania, Serbia, and Slovenia. Mean score achieved by HCPs was 52.2%. Paediatric gastroenterologists scored the highest (75.3%). Comparing the data with the study conducted in Central Europe in 2016, we found a significant rise ($p < 0.001$) in the knowledge of paediatric gastroenterologists. Also, HCPs who previously took part in the Focus IN CD project, achieved higher score (61.1% vs. 50.8%; $p < 0.001$).

Conclusion The knowledge about CD among HCPs in Danube region is not satisfactory. There has been a significant increase in the knowledge of paediatric gastroenterologists, showing the benefit of various awareness raising activities that were carried out recently.

Keywords Coeliac disease, Knowledge, Healthcare professionals, Danube region, Awareness

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Background

Celiac disease (CD) is a chronic autoimmune condition triggered by gluten and related prolamines in genetically predisposed individuals, affecting approximately 1% of the population [1–3]. Its clinical manifestations vary widely, from malabsorptive symptoms more common in younger children to abdominal pain, that is one of the most common gastrointestinal symptoms in older children and adolescents [2, 4]. Additionally, CD may manifest with extraintestinal symptoms or remain asymptomatic [2–6]. Its genetic component predisposes family members and associates with other conditions such as type-1 diabetes, immunoglobulin A (IgA) deficiency, autoimmune thyroid disease, and certain chromosomal abnormalities [1, 5].

Diagnosis relies on specific autoantibodies and characteristic small intestinal mucosal changes [1]. Recently, the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and European Society for the Study of Celiac Disease released updated guidelines for diagnosing CD in children and adults, respectively. [1, 7]. A notable disparity between the two sets of guidelines lies in the diagnostic approach. In children, CD can be accurately diagnosed without the need for intestinal biopsy if specific criteria are met [1, 3, 8–10]. This approach aims to streamline diagnosis and reduce invasive procedures. Although investigations into a similar no-biopsy approach for adults are underway, the lack of robust data necessitates biopsy confirmation in most countries. Therefore, while paediatric guidelines allow for a non-biopsy diagnostic pathway under certain conditions, biopsy remains the standard diagnostic method for confirming CD in adults across many nations [7, 11, 12]. The only treatment for CD is a lifelong adherence to a strict gluten-free diet [1, 13]. However, implementing and maintaining a gluten-free diet can be challenging due to the pervasive nature of gluten in many food products. Recognizing this difficulty, ongoing research has identified potential therapeutic targets grounded in the evolving understanding of CD's underlying mechanisms. These targets serve as the basis for developing new drugs aimed at complementing or enhancing the efficacy of the gluten-free diet. Despite these research endeavours, the gluten-free diet remains the only proven and reliable treatment for CD, underscoring the importance of dietary compliance in managing this condition [14].

Research indicates that healthcare professionals (HCPs) often possess inadequate knowledge about CD, contributing to poor disease recognition and diagnostic delays [15–20]. Numerous studies have highlighted the insufficient understanding of CD among HCPs, indicating the urgent need for improved education and awareness initiatives within the healthcare community [21–27].

Therefore, the aim of our study was to assess the knowledge about CD among HCPs in the Danube region.

Methods

The study was carried out between February 2021 and October 2021, as a part of the CD SKILLS project (DTP 571), co-financed by the EU Danube Transnational Programme.

Participants and study design

Healthcare professionals (HCPs) from eight countries within the Danube region (Austria, Croatia, Czech Republic, Hungary, Moldova, Romania, Serbia, and Slovenia), were invited to participate in a web-based questionnaire regarding CD. This questionnaire was developed as part of the Focus IN CD project and thereafter adapted and translated into the official languages of all participating countries. Comprising 22 questions (Supplementary material 1), the questionnaire was divided into three subsections: epidemiology with clinical presentation (7 questions), diagnostics (8 questions), and treatment with follow-up (7 questions). Each question was assigned a score based on its complexity, ranging from one to two points. The total score was then calculated as a percentage of the maximum score attainable for each subsection. Our analysis focused on evaluating the knowledge of HCPs responsible for managing CD patients, considering their specialty, years of work experience, and country of residence. We compared the scores of these HCPs with the results obtained from a similar study conducted in Central Europe as part of the Focus IN CD project in 2016 [21].

Statistical analysis

Statistical analysis was performed using IBM SPSS Statistics 24.0. One-way ANOVA and Independent Samples t-test were used for the analysis.

Results

Questionnaire was completed by 799 HCPs (75.5% female, median age 42 years) from Austria ($N=197$), Croatia ($N=75$), Czech Republic ($N=55$), Hungary ($N=58$), Moldova ($N=52$), Romania ($N=48$), Serbia ($N=237$) and Slovenia ($N=77$). The majority of respondents were paediatricians (68.6%), followed by internal medicine specialists (9.5%), general practitioners (6.5%), and other HCPs (Supplementary material 2). On average, HCPs achieved a mean score of 52.2%. The highest mean score was observed in the treatment and follow-up subsection, with a mean score of 61.9%, followed by the diagnostics subsection (48.2%) and the epidemiology with clinical presentation subsection (46.9%). There were significant differences observed among the included regions overall (Fig. 1) and also in different subsections ($p<0.001$). HCPs

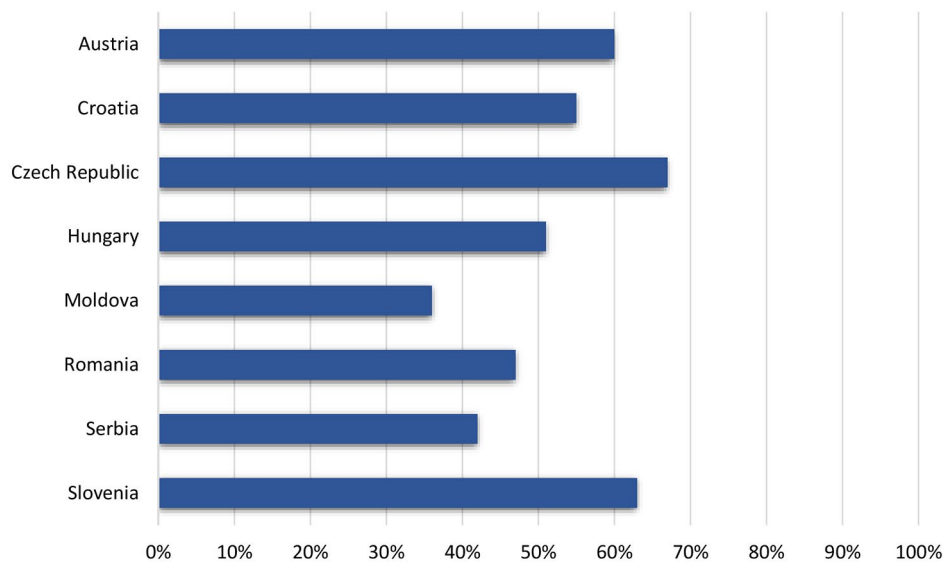


Fig. 1 Mean score achieved by HCPs according to the country of residence ($p < 0.001$)

from Czech Republic scored the highest (67%), followed by Slovene HCPs (63%) and Austrian HCPs (60%). The same ranking was found also for all the subsections.

HCPs who diagnose 0–10 new CD patients annually ($N=627$) achieved lower scores compared to those diagnosing more than 10 new CD patients per year (51% vs. 64.1%; $p < 0.001$). Similarly, HCPs with 10–20 years of experience ($N=114$) attained higher scores compared to those with 0–5 years, 5–10 years, and over 20 years of experience (61.5% vs. 49.2% vs. 56.7% vs. 57%; $p < 0.001$). Additionally, residents scored lower than specialists (47.8% vs. 55.5%; $p < 0.001$). Moreover, HCPs with personal experience of CD, either through personal diagnosis or having a family member or friend with CD ($N=167$), achieved significantly higher scores compared to others (57.6% vs. 50.7%; $p < 0.001$). Male HCPs scored higher than female counterparts (58.1% vs. 51.8%, $p < 0.001$).

Significant differences ($p < 0.001$) were observed among different specialties, with paediatricians (56.9%) and internal medicine specialists (51.7%) scoring higher than general practitioners (40.4%) and other specialists (37.7%).

When comparing paediatricians from different countries, it was found that Croatian paediatricians achieved the highest scores (68.6%), followed by paediatricians from the Czech Republic (67%) and Slovenia (65.6%) ($p < 0.001$). Moreover, comparing gastroenterologists (paediatric gastroenterologists [$N=72$] and internal medicine-gastroenterologists [$N=48$]) with primary care physicians (primary care paediatricians [$N=362$] and general practitioners [$N=52$]), it was observed that paediatric gastroenterologists scored significantly higher than internal medicine-gastroenterologists, primary care

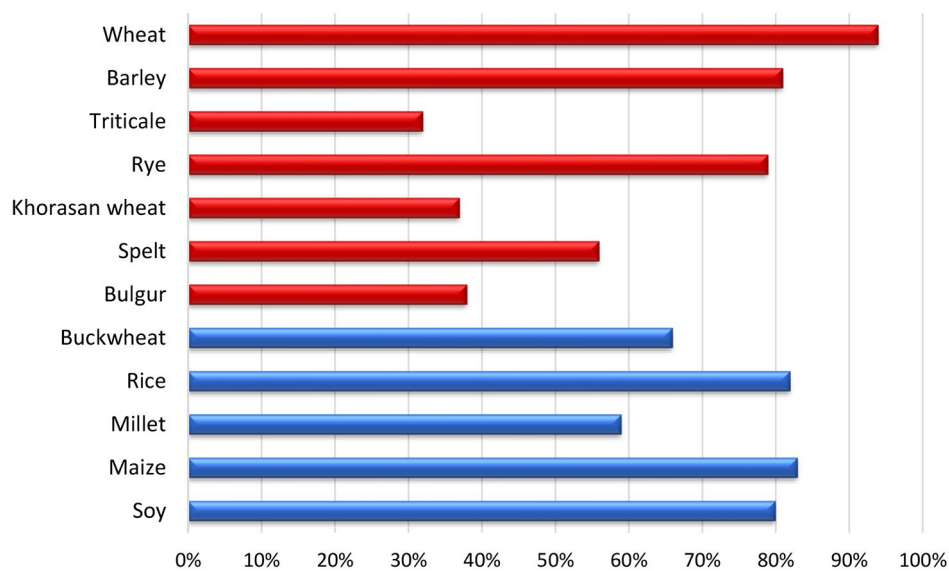
paediatricians, and general practitioners (mean score: 75.3% vs. 55.1% vs. 53.9% vs. 40.4%; $p < 0.001$). Among countries, Slovenian paediatric gastroenterologists achieved the highest scores (86.3%), followed by Croatian (80%) and Austrian paediatric gastroenterologists (79.1%) (Supplementary material 3).

Comparing the current data with a similar study conducted in Central Europe in 2016 [21], a significant increase in the knowledge of paediatric gastroenterologists was observed ($p < 0.001$) (Table 1). Additionally, the overall knowledge of HCPs in the Danube region in 2021 was slightly higher compared to Central Europe in 2016 (52.2% vs. 50.9%; NS). Furthermore, HCPs who previously participated in the Focus IN CD project ($N=69$; 22 paediatric gastroenterologists, 33 primary care paediatricians, 7 internal medicine-gastroenterologists and 7 other specialists) achieved a higher score compared to those who did not (61.1% vs. 50.8%; $p < 0.001$). Regarding the clinical presentation of CD, HCPs identified abdominal pain (68%), failure to thrive (67%), and abdominal distention (66%) as among the most common symptoms. While classical symptoms and signs of CD were generally well-recognized, many HCPs did not identify the asymptomatic form of the disease as an important clinical manifestation. When questioned about the treatment of CD and asked to recognize gluten-containing and gluten-free cereals, only 16.6% correctly identified all gluten-containing grains (Fig. 2).

HCPs stated that they mostly receive information about CD at seminars, lectures, and congresses (65.8%), on the internet (62.2%), from medical journals (57.3%) and from books.

Table 1 Results achieved by primary care physicians and gastroenterologists according to different subsections of the questionnaire in Central Europe [21] and Danube region

CENTRAL EUROPE 2016	GENERAL PRACTITIONERS (N=424)	PRIMARY CARE PAEDIATRICIANS (N=405)	PAEDIATRIC GASTROENTEROLOGISTS* (N=49)	INTERNAL MEDI- CINE GASTRO- ENTEROLOGISTS (N=20)
Overall mean score	53.4% (SD ± 16.5)	53.4% (± 15.5)	69.4% (± 10.7)	54.2% (± 9.4)
Epidemiology and clinical presentation	46.2% (SD ± 17.5)	46.3% (± 17.1)	60.8% (± 13.8)	51.7% (± 13.6)
Diagnostic procedure	40.4% (SD ± 26.2)	39.7% (± 27.8)	63.3% (± 23.3)	34.2% (± 14.8)
Treatment and follow-up	67.8% (SD ± 17.9)	68.1% (± 16.2)	80.8% (± 15.1)	68.5% (± 14.2)
DANUBE REGION 2021	GENERAL PRACTITIONERS (N=52)	PRIMARY CARE PAEDIATRICIANS (N=362)	PAEDIATRIC GASTROENTEROLOGISTS* (N=72)	INTERNAL MEDI- CINE GASTRO- ENTEROLOGISTS (N=48)
Overall mean score	40.4% (SD ± 14.2)	53.9% (± 15.9)	75.3% (± 13.9)	55.1% (± 12.5)
Epidemiology and clinical presentation	32.7% (SD ± 16.5)	47.8% (± 17.6)	69.9% (± 18.1)	50.7% (± 14.6)
Diagnostic procedure	36.2% (SD ± 18.6)	49.1% (± 22.8)	76.2% (± 15.4)	55.4% (± 22.3)
Treatment and follow-up	51.7% (SD ± 19.3)	65.5% (± 19.1)	80.6% (± 16.5)	59.9% (± 14.8)

* $p < 0.001$ **Fig. 2** The percentage of HCPs that correctly recognized gluten-containing (red) and gluten-free (blue) cereals

Discussion

Several studies have consistently revealed that the knowledge about coeliac disease among HCPs is inadequate. This assertion was further supported by our study conducted in the Danube region, where over 800,000 individuals are estimated to have CD. Leveraging the CD SKILLS project, which builds upon the groundwork laid by the Focus IN CD project under the EU Central Europe Programme, we were able to compare the results of our study with a similar one conducted in 2016 in Central Europe [21].

Despite knowledge remaining unsatisfactory (satisfactory level being mean score of 70% or above), we

observed a slight improvement in overall knowledge in the Danube region compared to Central Europe ($N=1381$), where the mean score was 50.9%, compared to 52.2% in the Danube region [21]. In both regions, knowledge about treatment and follow-up was highest. However, recognition of gluten-free and gluten-containing cereals remains unsatisfactory. The need to enhance knowledge about CD treatment was emphasized in the study by Malik et al. [28] where 12.3% of paediatricians believed that a gluten-free diet could be discontinued in the future. Similarly, approximately 25% of physicians in the study by Kozhakhmetova et al. [29] were unaware of the appropriate treatment for CD patients. In our study,

it is concerning that HCPs demonstrated the lowest knowledge about clinical presentation, indicating a failure to recognize various presentations of coeliac disease, despite adequately identifying the most common symptoms of CD.

Similar findings were reported in the study by Malik et al. [28], which highlighted poor awareness among paediatricians ($N=271$) regarding atypical clinical presentations of CD and its associations with other diseases. Furthermore, knowledge about diagnostic procedures was sub-optimal, and overall awareness about the disease and diagnostic guidelines was lacking [28]. Similarly, Shergill et al. [22] identified a low level of awareness about CD among Indian HCPs ($N=102$). As in the study by Malik et al. [28], atypical presentations of CD were poorly recognized [22]. This trend was also observed in the study by Kozhakhmetova et al. [29]. Similarly, only a minority of HCPs in our study were aware of asymptomatic CD, which hampers early recognition in this important subgroup.

In the study by Jinga et al. [23], poor knowledge about CD was also observed among physicians ($N=153$), particularly concerning prevalence, associated conditions, diagnostic recommendations, and treatment in adult patients. It's noteworthy that no paediatricians participated in this study [23]. Our study, along with the study conducted in Central Europe in 2016 [21], highlighted the importance of informal learning, as HCPs who had a family member or friend with CD demonstrated better knowledge compared to others.

Contrary to findings in the Central Europe study [21] and the study by Assiri et al. [27], we found that physicians who had been working in the field of CD for a longer duration exhibited greater knowledge compared to younger physicians. This trend was also observed in the study by Barzegar et al. [24], where physicians with over 10 years of experience demonstrated better knowledge. Similarly, Kozhakhmetova et al. [29] found that the most senior doctors (aged over 50 years) exhibited the best general knowledge, followed by the youngest age group, while the middle age group (40–50 years) showed the lowest awareness [29].

The study by Barzegar et al. [24] conducted in Iran revealed a lack of knowledge among HCPs regarding CD), particularly concerning its diagnosis and treatment. Similarly to our study, gastroenterologists exhibited higher knowledge about CD compared to general practitioners [24]. This aligns with findings from other studies, including those by Zipser et al. [25] in the United States ($N=132$), Assiri et al. [27] in Saudi Arabia ($N=109$), and Kozhakhmetova et al. [29] in Kazakhstan ($N=232$), which all highlighted poor knowledge about CD contributing to its underdiagnosis. Moreover, our study found that HCPs working in larger centres achieved higher scores

compared to those in smaller centres, which is likely because they are exposed to CD patients more frequently. Additionally, it appears that as one moves further east, overall knowledge about CD tends to be lower compared to more western countries. Furthermore, our study found that knowledge about CD was higher in regions located in the western part of the Danube region, which also geographically belongs to Central Europe.

In our study, paediatric gastroenterologists achieved the highest score, and compared to the study in Central Europe, there has been a significant increase in knowledge about CD among this group of HCPs. Interestingly, HCPs who participated in the Focus IN CD project scored significantly higher compared to others. This could be attributed to various awareness-raising activities implemented after 2016 as part of the Focus IN CD project, including the development of e-learning materials, brochures, booklets, and awareness campaigns conducted in recent years. Participants in our study were also asked about their main source of information about CD. Interestingly, books were found to be a less common source of information. This suggests that exploring new ways to provide information, such as e-tools or other digital products associated with CD-oriented projects, could be beneficial. The need for continuous training aimed at primary care physicians and general practitioners to improve early diagnosis was also recognized by Casella et al. [30].

We acknowledge several potential limitations of our study. One limitation is the low number of participating physicians from certain subspecialties, which hindered our ability to compare results among different countries. Also, during the first project (Focus in CD), much more general practitioners were participating, because in that project we were focusing more on the primary care general practitioners, whereas during the second project (CD SKILLS) our aim was to target paediatricians more. However, some general practitioners showed interest in participating, therefore we included their data as well. This could however be a reason for a positive selection bias whereby more interested/educated participants took part in the study. Additionally, the smaller number of participants from certain regions raises the risk of a selected population bias, wherein participants may not be fully representative of the healthcare provider population in those regions. Also, our questionnaire was unfortunately not designed in a way that could enable us to get deeper insight into the reasons behind the lack of knowledge. Therefore, we can only speculate that the reason is the lack of exposure to most recent information, including the recent guidelines during the formal education. We therefore designed educational and awareness rising events and published educational materials for HCPs that were distributed to different target groups including

healthcare professionals (students, residents, fellows, specialists).

However, the strength of our study lies in the relatively large number of participating physicians compared to most other studies on this topic. Additionally, the similarity of our study to our previous study in Central Europe allowed us to analyse the impact of various awareness-raising activities conducted as part of the Focus IN CD project.

Conclusions

In conclusion, the knowledge about CD among HCPs in the Danube region is not satisfactory. The highest scores achieved by paediatric gastroenterologists may be attributed to their heightened awareness of the burden of CD within this group. The significant increase in knowledge among paediatric gastroenterologists in Central Europe between 2016 and 2021 suggests the potential benefits of various awareness-raising activities conducted during this period, including those within the EU Focus IN CD project.

However, there is still a need for further improvements. Increasing awareness among primary care physicians and adult gastroenterologists is essential to enhance the management of CD patients and reduce diagnostic delays resulting from poor recognition of various clinical manifestations of CD and its associated conditions. It would be beneficial to assess whether diagnostic delays have shortened in countries previously involved in the Focus IN CD project and to evaluate the duration of delays in countries with poorer knowledge about CD. Continued efforts to improve CD awareness and education among HCPs are crucial for ensuring timely diagnosis and effective management of CD patients in the Danube region and beyond. In the scope of CD SKILLS project, we have in fact designed many awareness rising activities and published many educational materials in different languages at the end of the project. These are freely available on the project website (<https://dtp.interreg-danube.eu/approved-projects/cd-skills>). It would be also very interesting to see how the knowledge of participants will change in the future.

Abbreviations

CD	Coeliac disease
HCPs	Healthcare professionals
IgA	Immunoglobulin A
ESPGHAN	European Society for Paediatric Gastroenterology, Hepatology and Nutrition

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12876-024-03349-x>.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

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Author contributions

PR. and JD. contributed to the literature search, figures, study design, data collection, data analysis, data interpretation and writing of the final manuscript. IC., JD., ND., JG., ACH., MK., IRKS., TK., MM., ZM., VP., AP., TR. and PS. contributed to the conception of the study, adaptation of questions to reflect regional needs, provided translation into languages of participating countries, disseminated the questionnaires in their respective countries and participated in data collection. All authors critically revised and confirmed the final version of the manuscript.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Ethics approval and consent to participate

The study was approved by the National Medical Ethics Committee of the Republic of Slovenia (0120 – 12/2021/9). All participants gave their informed consent to participate in the study.

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