

Prospective Study

Knowledge regarding celiac disease among healthcare professionals, patients and their caregivers in Turkey

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Celiac disease (CD) is one of the most prevalent chronic disorders. The clinical manifestations of CD are diverse and may present with gastrointestinal findings, extra-intestinal findings or no symptoms. Although there has been a marked increase in the prevalence of CD in the past 30 years, up to 95% of patients with CD remain undiagnosed. As most cases have atypical signs or no symptoms, the diagnosis of CD is either missed or delayed. In addition, one of the most important reasons for the delay in diagnosis may be the poor knowledge of healthcare professionals (HCPs) regarding CD.

AIM

To evaluate the knowledge of HCPs, patients and their caregivers (parents) regarding CD.

METHODS

The current study was carried out between June 2021 and February 2022 prospectively, as part of the Focus IN CD project. Patients with CD and their caregivers participated in the study from 6 different cities in Turkey. General practitioners, pediatricians, pediatricians with other subspecialties and pediatric gastroenterologists from different cities participated in the study.

RESULTS

The questionnaire was completed by 348 HCPs, 34 patients with CD, and 102 mothers and 34 fathers of patients with CD. Most of the participants were general practitioners (37.07%). There were 89 (25.57%) pediatricians and 72 (20.69%) pediatric gastroenterologists in the study. The highest score in all categories was achieved by pediatric gastroenterologists. There were significant differences between the four groups of HCPs in terms of the subsections of overall mean score, epidemiology and clinical presentation, treatment and follow-up. No significant difference was found between the groups (patients with CD, mothers of patients with CD and fathers of patients with CD) in terms of the questionnaire subsections.

CONCLUSION

The level of knowledge on CD among HCPs, patients and their caregivers was unsatisfactory. We consider that it is necessary to increase awareness and to develop e-learning activities on CD among HCPs, patients and their caregivers. Consequently, they may benefit from e-learning programs similar to the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusinced-en>).

Key Words: Celiac disease; Healthcare professionals; Knowledge; Patients

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Core Tip: In this study, we aimed to evaluate the knowledge of healthcare professionals (HCPs), patients and their caregivers (parents) regarding celiac disease (CD). We found that the level of knowledge on CD among HCPs, patients and their caregivers was unsatisfactory. We consider that it is necessary to increase awareness and to develop e-learning activities on CD among HCPs, patients and their caregivers. Patients, their caregivers, and HCPs may benefit from e-learning programs similar to the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusinced-en>).

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INTRODUCTION

One type of systemic autoimmune illness is celiac disease (CD), which is characterized by a combination of various degrees of small bowel damage and clinical manifestations triggered by gluten ingestion in people who are genetically vulnerable[1,2]. It is one of the most common chronic disorders. The prevalence of CD is estimated to be approximately 1% in the general population worldwide[1,2].

The clinical manifestations of CD are diverse and may present with gastrointestinal findings, extra-intestinal findings or no symptoms[1-3]. Constipation, recurrent abdominal pain, bloating, and chronic diarrhea are the primary gastrointestinal symptoms. Short stature, iron deficiency anemia, and poor growth, decreased bone mineral density, dermatitis herpetiformis, delayed puberty, alopecia, neurological symptoms, headache, joint manifestations, fatigue, stomatitis, infertility, and unexplained abnormal liver enzymes are common extra-intestinal symptoms[1]. The definitive diagnosis of CD is carried out by evaluating clinical findings, positivity of CD specific serological tests, and characteristic histological findings in the small intestinal mucosa[1].

In the past 30 years, there has been a noticeable rise in the prevalence of CD, which may be attributed to a combination of factors including greater medical education and awareness of CD as well as the utilization of very sensitive and specific diagnostic tests[4,5]. Due to increased awareness, up to 95% of patients with CD remain undiagnosed[6,7]. It has been reported that the delay in diagnosis is between 4

and 10 years[8-10]. Undiagnosed cases are very high even in developed countries. As most cases have atypical signs or no symptoms, the diagnosis of CD is either missed or delayed[11,12]. Other factors that may contribute to delayed or missed diagnosis include the scarcity of serological diagnostic tests in developing countries and a scarcity of experienced specialists in this field[13].

Early diagnosis is crucial in order to prevent long-term complications of CD such as malnutrition, osteoporosis, infertility, small bowel cancer, and lymphoma[14].

One of the most important reasons for the delay in diagnosis may be the poor knowledge of healthcare professionals (HCPs) regarding CD. In addition, insufficient information on CD may affect adherence to a gluten-free diet. As CD affects many systems such as neurological, hematological and reproductive systems, it is very important to adhere to a strict gluten-free diet to prevent long-term complications[2,11]. There are limited studies investigating the knowledge regarding CD among HCPs, patients and their caregivers. To our knowledge, there are no studies on this issue in Turkey. The aim of the present study was to evaluate the knowledge of HCPs, patients and their caregivers (parents) regarding CD.

MATERIALS AND METHODS

The current study was carried out between June 2021 and February 2022 prospectively, as part of the Focus IN CD project. The local Ethics Committee approved the study (Sanko University, Gaziantep, Turkey, June 2, 2021/06).

Participants and study design

Patients with CD and their caregivers participated in the study from 6 different cities in Turkey. General practitioners, pediatricians, pediatricians with other subspecialties and pediatric gastroenterologists from different cities participated in the study.

Patients with CD who were followed up and treated in pediatric gastroenterology outpatient clinics were selected. Face to face communication with patients was conducted. Those who voluntarily agreed to participate were included in the study. Communication with HCPs was established by face to face communication and by phone, and then a link was sent *via* WhatsApp to those who voluntarily participated in the study. Also, HCPs and patients, who did not answer all the questions, were excluded from the study.

We analyzed the differences in the knowledge on CD among HCPs and differences in the knowledge between patients with CD and their caregivers.

HCPs, patients with CD and their caregivers were asked to answer and complete web-based questions on CD (for HCPs https://tr.surveymonkey.com/r/Q2_Focus_in_CD_TUR) (for patients with CD and their caregivers https://tr.surveymonkey.com/r/Q3_CD_in_Focus_TUR).

The questionnaire for HCPs included 21 questions in total, which were divided into 3 subgroups: Epidemiology and clinical presentation (7 questions), diagnostic methodology (7 questions), and treatment with follow-up (7 questions). Fourteen questions were included in the questionnaire for patients and parents, and they were categorized into two subgroups: Epidemiology, clinical presentation, and diagnostic methods (7 questions) and treatment with follow-up (7 questions). All 14 questions were similar to the questions for HCPs. Nine of those questions were exactly the same. The remaining 5 questions required fewer answers from patients and their relatives.

Statistical analysis

Version 22.0 of the Statistical Package for Social Sciences program was used for the statistical analysis (SPSS Inc; Chicago, IL, United States). Descriptive statistics were used for frequency, percentage, and mean \pm standard deviation (SD). To ascertain if the data distribution adhered to a normal distribution, the Kolmogorov-Smirnov test was utilized. For nominal data, the independent samples *t*-test was performed. To compare ranges of numerical variables, the Mann-Whitney U test was employed. For the comparison of categorical variables, the chi-square test was used. One-way analysis of variance (ANOVA) for independent groups was used to compare the groups. When there was a significant difference between the groups, Post Hoc Multiple Comparison Tests were performed to determine which groups showed a statistically significant difference.

RESULTS

Analysis of healthcare professionals' knowledge

The questionnaire was completed by 348 HCPs. Most of the participants were general practitioners (37.07%). There were 89 (25.57%) pediatricians and 72 (20.69%) pediatric gastroenterologists in the study (Table 1). Forty-six HCPs who did not answer all the questions, were excluded from the study.

Table 1 The distribution of health care professionals according to specialty

Specialty	Number (%), n = 348
General practitioners	129 (37.07)
Pediatricians	89 (25.57)
Pediatricians with other subspecialties	58 (16.67)
Pediatric gastroenterologists	72 (20.69)

The highest score in all categories was achieved by pediatric gastroenterologists. There were significant differences between the four groups of HCPs in terms of the subsections of overall mean score, epidemiology and clinical presentation, treatment and follow-up ($P < 0.001$). There was a significant difference between the four groups of HCPs in terms of the subsections of diagnostic procedure ($P = 0.023$). After performing Post Hoc Multiple Comparison Tests, a difference was detected between pediatric gastroenterologists and the other groups. No one answered all the questions correctly. When analyzing the questionnaire subsections, we detected a lower mean score in the subsection on diagnostic procedure in the pediatricians with different subspecialties in comparison to the other HCPs (Table 2).

Healthcare professionals mostly received information on CD from books (68.32%), the internet (67.6%), at seminars, lectures, and congresses (66.0%) and medical journals (56.7%).

Analysis of patients and caregivers' knowledge

The questionnaire was completed by 34 patients with CD, 102 mothers and 34 fathers of patients with CD. Thirty-two caregivers, who did not answer all the questions, were excluded from the study.

No significant difference was found between the groups (patients with CD, mothers of patients with CD and fathers of patients with CD) in terms of all the questionnaire subsections ($P > 0.05$) (Table 3). None of the patients with CD or their caregivers answered all the questions correctly. The highest mean score in all subsections was achieved by the fathers of patients with CD. Of the 168 patients with CD and their caregivers (parents), 19 (11.3%) of them were members of the Local Celiac Society.

There was no significant difference between the groups (patients with CD, mothers of patients with CD and fathers of patients with CD) in terms of duration of diagnosis ($P > 0.05$). In addition, no significant difference was found between the groups (patients with CD, mothers of patients with CD and fathers of patients with CD) in terms of educational level ($P > 0.05$).

DISCUSSION

Celiac disease is one of the most common systemic diseases. The clinical manifestations of CD are very diverse[1,3]. Delayed diagnosis can result in many complications such as growth retardation, osteopenia, delayed puberty, infertility, and malignancy[2,14,15]. Despite the development of sensitive and specific tests in recent years, the majority of patients with CD is still not diagnosed[1,2,10].

One of the most important reasons for delays in diagnosis may be poor knowledge of HCPs regarding CD[16,17]. The delay in diagnosis has been reported to be up to 10 years[8-10]. According to reports, the number of undiagnosed cases is estimated to be very high. Due to the lack of clinically obvious symptoms in most CD patients, the diagnosis is often missed or delayed[11,12]. Therefore, awareness in HCPs regarding CD is very important in order to diagnose more patients.

In the present study, family physicians and pediatricians had lower scores in the survey than pediatric gastroenterologists, and there was a statistically significant difference between them. It is very important to increase the knowledge of family physicians and pediatricians on CD, as they represent the first HCP for potential patients with CD[16,17]. Consistent with the present findings, Riznik *et al*[17] and Zipser *et al*[18] also strongly suggested that the level of knowledge in family physicians regarding CD symptoms and related diseases should be increased. Both our study and the results of these two studies have revealed that increasing the level of knowledge and awareness of CD in family physicians and pediatricians in order to refer patients thought to have CD to pediatric gastroenterologists may reduce the delay in CD diagnosis.

Assiri *et al*[16] reported that the level of knowledge in young doctors is better. As CD is not a rare disease, more detailed information on CD is now known about the disease in medical faculties. On the other hand, Barzegar *et al*[19] found that the level of knowledge regarding diagnosis and treatment by doctors who have been practicing medicine for more than 10 years was higher than that in young doctors. In contrast to these studies, no difference was detected in the present study concerning this issue.

Table 2 Results achieved by healthcare professionals according to the different questionnaire subsections on celiac disease

	General practitioners	Pediatricians	Pediatricians with other subspecialties	Pediatric gastroenterologists	P value
Overall mean score	54.18 ± 21.11	55.20 ± 20.90	50.29 ± 22.26	66.37 ± 15.32	< 0.001
Epidemiology and clinical presentation	66.87 ± 17.98	67.17 ± 17.79	62.01 ± 18.98	74.79 ± 17.12	< 0.001
Diagnostic procedure	40.38 ± 24.15	45.24 ± 24.78	40.29 ± 25.36	51.64 ± 22.94	0.023
Treatment and follow-up	55.29 ± 32.47	53.18 ± 31.76	48.56 ± 33.08	72.68 ± 18.82	< 0.001

Table 3 Results of celiac patients and parents according to the questionnaire

	Mothers of patients with CD <i>n</i> = 102	Fathers of patients with CD <i>n</i> = 34	Patients with CD <i>n</i> = 34	P value
Overall mean score	45.78 ± 18.10	48.63 ± 19.31	38.28 ± 19.22	0.055
Epidemiology, clinical presentation and diagnosis	47.65 ± 15.03	51.95 ± 17.12 ^a	41.00 ± 17.40 ^a	0.018
Treatment and follow-up	43.90 ± 28.02	45.31 ± 27.24	35.56 ± 27.72	0.260

^aThere was a significant difference between two groups. CD: Celiac disease

In the current study, excluding the pediatric gastroenterologists, approximately half of the questions were answered correctly. Interestingly, even pediatric gastroenterologists answered about half of the questions correctly on the diagnostic procedure. These results were unsatisfactory but in line with previous studies[16,17,19-22].

As expected, pediatric gastroenterologists scored highest of all the groups in the study, their awareness of CD was high, but an average of 50% correct answers were given in the section on diagnostic procedure. As we found that pediatric gastroenterologists have insufficient knowledge of the 2020 ESPGHAN guideline for diagnosing CD in the survey, we considered that the current ESPGHAN guideline is not followed entirely by pediatric gastroenterologists. Poor knowledge among HCPs leads to increased numbers of undiagnosed cases[19,20,23-25].

In the present study, we determined that the knowledge and awareness levels of the patients and their caregivers on CD were both low and unsatisfactory.

The fathers had a mean score greater than 50% in the subsection on epidemiology, clinical presentation and diagnosis, the mean scores of patients with CD, and parents of patients with CD were below 50% in all other subgroups. We found that the level of knowledge in the subsection on epidemiology, clinical presentation and diagnosis in patients with CD, mothers of patients with CD and fathers of patients with CD was higher than that in the subsection of treatment and follow-up. There are not only compatible studies but also incompatible studies with the present study[17,26-28]. In contrast to our study, higher scores were found in the subsection on treatment and follow-up[17,26]. The authors concluded that families are in charge of their children's nutrition and are more cautious around them[17, 26]. It has been shown that 46%-52% of the parents were members of the Celiac Society; therefore, the authors thought that the scores were low[27,28]. Consistent with previous studies, only 11.3% of the parents were members of the Regional Celiac Support Association. Membership of associations is very important in terms of informing and raising awareness of the disease. We suggest that patients and their caregivers should be directed to membership of these associations. Also, we should increase the level of knowledge by organizing conferences on CD at regular intervals.

The mean score of the patients with CD was lower than those of parents in the current study. The results of our study also support the view that education is an important factor in increasing knowledge and awareness regarding CD in patients. It was also shown that knowledge of epidemiology, diagnosis and treatment increases significantly after a training program[29,30].

Limitations: There are several limitations in the current study. First, as the current study was web-based, we excluded 46 HCPs and 32 celiac patient caregivers who did not complete the entire questionnaire. Second, we were unable to make regional comparisons between HCPs and caregivers, as the majority of HCPs and celiac patient caregivers did not specify the region in which they lived. Third, a small number of patients and their caregivers participated in the study.

CONCLUSION

Despite these limitations, the level of knowledge on CD among HCPs, patients and their caregivers was unsatisfactory. We consider that it is necessary to increase awareness and to develop e-learning activities on CD among HCPs, patients and their caregivers. They may benefit from e-learning programs similar to the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusinced-en>). A higher level of knowledge will substantially reduce the number of undiagnosed patients, allow for earlier diagnosis, and enhance overall quality of life. Patients with CD and their caregivers should be guided and encouraged to become members of regional Celiac Support Associations. E-learning activities should be organized through these associations. It is very important for the patients to be more informed regarding the disease in terms of compliance with the gluten-free diet. The better the compliance with the diet, the fewer complications will arise.

ARTICLE HIGHLIGHTS

Research background

Celiac disease (CD) is a systemic autoimmune disorder characterized by a combination of various degrees of small bowel damage and diverse clinical manifestations triggered by gluten ingestion in people who are genetically vulnerable. It is one of the most prevalent chronic disorders. The clinical manifestations of CD are diverse and may present with gastrointestinal findings, extra-intestinal findings or no symptoms. Up to 95% of patients with CD remain undiagnosed. As most cases have atypical signs or no symptoms, the diagnosis of CD is either missed or delayed. In addition, one of the most important reasons for the delay in diagnosis may be the poor knowledge of healthcare professionals (HCPs) on CD.

Research motivation

There are limited studies investigating the knowledge on CD among HCPs, patients and their caregivers. To our knowledge, there are no studies on this issue in Turkey. Thus, we aimed to evaluate the knowledge on CD among HCPs, patients and their caregivers.

Research objectives

To evaluate the knowledge on CD among HCPs, patients and their caregivers.

Research methods

The current study was carried out between June 2021 and February 2022 prospectively, as part of the Focus IN CD project. Patients with CD and their caregivers participated in the study from 6 different cities in Turkey. In addition, general practitioners, pediatricians, pediatricians with other subspecialties and pediatric gastroenterologists from different cities participated in the study.

Research results

The questionnaire was completed by 348 HCPs, 34 patients with CD, 102 mothers and 34 fathers of patients with CD. Most of the participants were general practitioners (37.07%). There were 89 (25.57%) pediatricians and 72 (20.69%) pediatric gastroenterologists in the study. The highest score in all categories was achieved by pediatric gastroenterologists. There were significant differences between the four groups of HCPs in terms of the subsections on overall mean score, epidemiology and clinical presentation, treatment and follow-up. There was no significant difference between the groups (patients with CD, mothers of patients with CD and fathers of patients with CD) in terms of the questionnaire subsections.

Research conclusions

The level of knowledge on CD among HCPs, patients and their caregivers was unsatisfactory. We consider that it is necessary to increase awareness and to develop e-learning activities on CD among HCPs, patients and their caregivers. They may benefit from e-learning programs similar to the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusinced-en>). A higher level of knowledge will substantially reduce the number of undiagnosed patients, allow for earlier diagnosis, and improve the quality of life.

Research perspectives

According to the current study, we believe that patients, their caregivers, and HCPs may benefit from e-learning programs similar to the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusinced-en>).

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FOOTNOTES

Author contributions: Sahin Y designed the study, analyzed the data, interpreted the data, conceived the study, was involved in the statistical analysis, and wrote the manuscript; Sevinc E, Bayrak NA, Varol FI, Akbulut UA, and Bukulmez A collected the data, and analyzed the data; All authors have read and approved the final manuscript.

Institutional review board statement: The Local Ethics Committee approved the study (Sanko University, Gaziantep, Turkey, June 2, 2021/06).

Informed consent statement: Informed consent was obtained from all participants.

Conflict-of-interest statement: All the authors declare that they have no conflict of interest.

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CONSORT 2010 statement: The authors have read the CONSORT Statement – checklist of items, and the manuscript was prepared and revised according to the CONSORT Statement – checklist of items.

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