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Prospective Study

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

Sahin Y *et al.* Knowledge about celiac disease

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Abstract

BACKGROUND

It's one of the most prevalent chronic disorders to have celiac disease (CD). 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. Since most of the cases have atypical signs or no symptoms, the diagnosis

of CD is either missed or delayed. In addition to that, one of the most important reasons for the delay in diagnosis may be the poor knowledge of healthcare professionals (HCPs) about CD.

AIM

To evaluate the knowledge of HCPs, patients and their care givers (parents) about CD.

METHODS

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

RESULTS

The questionnaire was completed by 348 health care professionals (HCPs), 34 patients with celiac disease, 102 mothers and 34 fathers of patients with celiac disease. 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 of all categories was achieved by pediatric gastroenterologists. There were significant differences between 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 celiac disease, mothers of patients with celiac disease and fathers of patients with celiac disease) in terms of all the subsections of questionnaire.

CONCLUSION

The level of knowledge about CD among HCPs, patients and their care givers was not at a satisfactory level. We consider that it is needed to increase awareness and to

develop e-learning activities about CD among HCPs, patients and their caregivers. Consequently, they may benefit from e-learning programs like the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusincd-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 health care professionals (HCPs), patients and their care givers (parents) about celiac disease (CD). We found that the level of knowledge about CD among HCPs, patients and their care givers is not at a satisfactory level. We consider that it is needed to increase awareness and to develop e-learning activities about CD among HCPs, patients and their caregivers. Patients, their caregivers, and HCPs may benefit from e-learning programs like the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusincd-en>).

INTRODUCTION

One type of systemic autoimmune illness is celiac disease (CD) 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). 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 the increased awareness, up to 95% of patients with celiac disease 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. Since most of the cases have atypical signs or no symptoms, so 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 ¹³serological 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) about CD. In addition, insufficient information about CD may affect adherence to a gluten-free diet. Since CD affects many systems such as neurological, hematological and reproductive systems, it is very important to adhere a strict gluten-free diet to prevent long-term complications (2,11). There are limited studies investigating the knowledge about CD among HCPs and patients and their caregivers. According to our knowledge, there is no study about that issue in Turkey. The aim of the study was to evaluate the knowledge of HCPs, patients and their care givers (parents) about CD.

MATERIALS AND METHODS

The current study was carried out between June 2021 and February 2022 prospectively, as a part of the Focus IN CD project. Local Ethics Committee approved the study before the study (Sanko University, Gaziantep, Turkey, 02 June 2021/06).

Participants and Study Design

Patients with CD and their caregivers participated in the study from 6 different cities of our country. General practitioners, pediatricians, pediatricians 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 were done. Those who voluntarily agreed to participate in the study were included in the study. Communication with HCP was established by face to face and 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 analysed the differences in the knowledge about CD among HCPs and differences in the knowledge between patients with celiac disease and their caregivers.

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

The questionnaire for HCP included 21 questions in total, which was 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 the same as HCP's questions. Nine of those questions were exactly the same. The remaining 5 questions required less answers for patients and their relatives.

7 Statistical analysis

Version 22.0 of the Statistical Package for Social Sciences program was used for the statistical analysis (SPSS Inc; Chicago, IL, USA). Descriptive statistics were used for frequency, percentage, and mean \pm standard deviation (SD). To ascertain if the data's 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 ANOVA analysis of variance test for independent groups was used to compare the groups.

RESULTS

Healthcare Professionals' Knowledge Analysis

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). 46 HCPs who did not answer all the questions, were excluded from the study.

The highest score of all categories was achieved by pediatric gastroenterologists. There were significant differences between 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 no significant difference between four groups of HCPs in terms of the subsections of diagnostic procedure ($P = 0.023$). No one answered all the questions correctly. When analyzing the subsections of questionnaire, we detected 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 about CD from books (68.32%), on the internet (67.6%), at seminars, lectures, and congresses (66.0%) and medical journals (56.7%).

Patients and Caregivers' Knowledge Analysis

The questionnaire was completed by 34 patients with celiac disease, 102 mothers and 34 fathers of patients with celiac disease. 32 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 subsections of questionnaire ($p>0.05$) (Table 3). No patients with celiac disease and their caregivers answered all the questions correctly. But the highest mean score in all subsections was achieved by the fathers of patients with celiac disease. Of the 168 patients with celiac disease 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 celiac disease, mothers of patients with celiac disease and fathers of patients with celiac disease) in terms of duration of diagnosis ($p>0.05$). In addition to that, 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). Delaying in diagnosis can give rise to many complications such as growth retardation, osteopenia, delayed puberty, infertility, and malignancy (2,14,15). Despite fact that the development of sensitive and specific tests in recent years, the majority of patients with celiac disease is still not diagnosed (1,2,10).

One of the most important reasons for delaying in diagnosis might be poor knowledge of HCPs about CD (16,17). The delay in diagnosis the delayed diagnosis of has been reported to be up to 10 years. (8-10). According to the reports, the number of undiagnosed cases is estimated to be very high. Due to the lack of clinically obvious CD

symptoms in most CD patients, the diagnosis is often missed or delayed (11,12). Therefore, awareness of HCPs about CD is very important to diagnose more patients.

In the present study, family physicians and pediatricians had lower scores in 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 about CD, as they represent the first application point for potential patients with CD (16,17). As consistent with the present study, Riznik *et al* (17) and Zipser *et al* (18) also strongly suggested that the level of knowledge of family physicians about CD symptoms and related diseases should be increased. Both our study and the results of these two studies revealed that increasing the level of knowledge and awareness of family physicians and pediatricians about the disease in order to refer patients thought to have CD to pediatric gastroenterologists may reduce the delay in diagnosis of CD.

Assiri *et al* (16) reported that the level of knowledge of young doctors is better. Since it is known that CD is not a rare disease compared to the past, more detailed information on CD has been given about the disease in medical faculties in recent years. On the other hand, Barzegar *et al* (19) found that the level of knowledge in diagnosis and treatment of the doctors who have been practicing medicine for more than 10 years is higher than young doctors. In contrast to those studies, no difference was detected in the present study.

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

As expected, pediatric gastroenterologists scored the highest in all groups in the study, their awareness of CD was high, but an average of 50% correct answers were given in the section of diagnostic procedure. As the information of the 2020 ESPGHAN guideline for diagnosing CD was inadequate, we considered that the current ESPGHAN

guideline is not followed entirely by pediatric gastroenterologists. Poor knowledge among HCPs leads to increased number 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 about CD were both low and unsatisfactory.

The fathers had a mean score above 50 percent in the subsection of epidemiology, clinical presentation and diagnosis, the mean scores of patients with celiac disease, parents of patients with celiac disease were below 50% in all other subgroups. We found that the level of knowledge in the subsection of epidemiology, clinical presentation and diagnosis in patients with celiac disease, mothers of patients with celiac disease and fathers of patients with celiac disease is higher than the subsection of treatment and follow-up. There are not only studies compatible and but also incompatible studies with the present study (17,26-28). Contrary to our study, it has been found higher scores in the subsection of 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 have membership of the celiac society, therefore the authors thought that the scores were low (27,28). Consistent with previous studies, there were only 11.3% of the parents who are members of Regional Celiac Support Association. Membership in associations is very important in terms of informing and raising awareness about the disease. We suggest that patients and their caregivers should be directed to membership in the association. Also, we should increase the level of knowledge by organizing conferences about 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 about CD for patients. And it has also showed 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, since the current study was web-based, **we had to exclude** 46 HCPs and 32 celiac patient caregivers who did not respond to 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, there was a small number of patients and their caregivers participated in the study.

CONCLUSION

Despite limitations, the level of knowledge about CD among HCPs, patients and their caregivers was not at a satisfactory level. We considered that it is needed to increase awareness and to develop e-learning activities about CD among HCPs, patients and their caregivers. They may benefit from e-learning programs like the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusincd-en>). A higher level of knowledge will substantially reduce the number of undiagnosed patients, allow for earlier diagnosis, and also enhance overall quality of life. Patients with CD and their caregivers should be guided and encouraged to become members of regional celiac support association. E-learning activities should be organized through these associations. It is very important for the patients to be more informed about the disease in terms of compliance with the gluten-free diet. The better the compliance with the diet, the less complications will be.

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's 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 celiac disease remain undiagnosed. Since most of the cases have

atypical signs or no symptoms, so the diagnosis of CD is either missed or delayed. In addition to that, one of the most important reasons for the delay in diagnosis may be the poor knowledge of healthcare professionals (HCPs) about CD.

Research motivation

There are limited studies investigating the knowledge about celiac disease among healthcare professionals and patients and their caregivers. According to our knowledge, there is no study about that issue in our country. Because of that, we aimed to evaluate the knowledge about celiac disease among healthcare professionals and patients and their caregivers.

Research objectives

To evaluate the knowledge about celiac disease among healthcare professionals and patients and their caregivers

Research methods

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

Research results

The questionnaire was completed by 348 health care professionals (HCPs), 34 patients with celiac disease, 102 mothers and 34 fathers of patients with celiac disease. 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 of all categories was achieved by pediatric gastroenterologists. There were significant differences between four groups of HCPs in terms of the subsections of

overall mean score, epidemiology and clinical presentation, treatment and follow up. There was no significant difference between the groups (patients with celiac disease, mothers of patients with celiac disease and fathers of patients with celiac disease) in terms of all the subsections of questionnaire.

Research conclusions

The level of knowledge about CD among HCPs, patients and their care givers was not at a satisfactory level. We consider that it is needed to increase awareness and to develop e-learning activities about CD among HCPs, patients and their caregivers. They may benefit from e-learning programs like the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusincd-en>). A higher level of knowledge will substantially reduce the number of undiagnosed patients, allow for earlier diagnosis, and also 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 like the one created as part of the EU-funded project Focus IN CD (<https://www.celiacfacts.eu/focusincd-en>).

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Footnotes

Institutional review board statement: Local Ethics Committee approved the study before the study (Sanko University, Gaziantep, Turkey, 02 June 2021/06).

Informed consent statement: The informed consent was obtained for all participants.

Conflict-of-interest statement: None

Data sharing statement: The data on the findings of this paper are all included in the tables

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TABLES

Table 1. The distribution of health care professionals according to the specialty

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

Table 2. Results achieved by pediatric gastroenterologists and other HCP according to the different questionnaire of celiac disease

	Genel practitioners		Pediatricians		Pediatric	
	p		other subspecialties		gastroenterologists	
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		
Treatment and follow up	55.29±32.47	53.18±31.76	48.56±33.08	72.68±18.82	<0.001	

*If p<0.0083 is, the mean difference is significant

1

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

	Mothers of patients with CD with CD n=102	Fathers of patients with CD n=34	Patients with CD n=34	Patients
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*	41.00±17.40*	
Treatment and follow up	43.90±28.02	45.31±27.24	35.56±27.72	0.260

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