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ORIGINAL ARTICLE

Gastroenterology: Celiac Disease

Celiac disease in North America: What is the current practice of pediatric gastroenterology providers?

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Abstract

Objectives: While guidelines exist for the diagnosis and management of pediatric celiac disease (CeD), current practices in North America are not well-described. This study aimed to explore current practice patterns to identify gaps and direct future clinical, training and research initiatives.

Methods: A 23-item survey designed by the Celiac Disease Special Interest Group was distributed electronically to its members. Questions explored four themes: (1) screening and diagnosis pre and post the coronavirus disease (COVID)-19 pandemic, (2) treatment and monitoring, (3) family screening and transition of care, and (4) CeD focused training.

Arunjot Singh and Jocelyn Silvester contributed equally to this study.

Edward J. Hoffenberg and Jenna K. Dowhaniuk shared last authorship.

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Results: The survey response rate was 10.8% (278/2552). Most respondents were from the United States (89.9%, $n = 250$) and Canada (8.6%, $n = 24$). While endoscopy remained the gold standard, serology-based diagnosis was accepted by 47.5% (132/278). In response to the COVID-19 pandemic, 37.4% of providers changed their diagnostic practice. Barriers to care included: lack of insurance coverage for dietitians, wait times, and lack of CeD focused training. During fellowship 69.1% (192/278) reported no focused CeD training.
Conclusion: Survey results revealed practice variation regarding the diagnosis and management of CeD in North America including a substantial proportion accepting non-biopsy, serology-based diagnosis, which increased during the COVID-19 pandemic. Variations in screening, diagnosis, interval surveillance, and family screening were also identified. Dedicated CeD education in pediatric gastroenterology fellowship may be an opportunity for standardizing practice and advancing research. Future North American guidelines should take current care patterns into consideration and develop new initiatives to improve care of children with CeD.

KEYWORDS
clinical practice, endoscopy, training

1 | INTRODUCTION

Celiac disease (CeD) is a gluten-driven enteropathy caused by immune dysregulation in genetically susceptible individuals.[1] While the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) published guidelines for diagnosis and management of pediatric CeD in 2005,[2] current practices in North America are not well-described.[2–4] This is of particular interest given the rise of gluten-related disorders, and the publication of European Society for Paediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) CeD guidelines in 2012 and updated in 2020 that offer a non-endoscopic diagnosis approach.[5,6] In addition, understanding the practice of North American pediatric gastroenterology providers in 2021 will identify impacts from the coronavirus disease (COVID)-19 pandemic, limited resources, and convoluted healthcare coverages.

This survey-based study sought to understand the expertise and practice patterns of NASPGHAN providers for the diagnosis and management of children with CeD, with the hope that the information would serve to inform updates to North American clinical guidelines, identify gaps in care, align clinical initiatives of pediatric CeD centers and community practices, and direct future research endeavors.

What is Known

- The gold standard for diagnosis of celiac disease (CeD) is an upper endoscopy with biopsy.
- The European Society of Paediatric Gastroenterology, Hepatology and Nutrition published guidelines outlining criteria for serologic-based diagnosis in children with CeD.
- Laboratory testing and dietitian assessment are essential in CeD management.

What is New

- Despite no recent North American guidelines, a considerable proportion of North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) respondents offer non-biopsy serologic diagnosis.
- Celiac surveillance practice varies and barriers to seeing a dietitian are common.
- Despite the high incidence of CeD in children, over two-thirds of respondents had not received any additional training in CeD during fellowship.

2 | METHODS

This survey of pediatric gastroenterology providers was conducted from September 2021 to January 2022. The study protocol was approved by the institutional review board at the Children's Hospital of Philadelphia (Supporting Information File 1).

2.1 | Participants

Eligible participants had to be active NASPGHAN members and practicing clinicians (e.g., gastroenterologists, fellows, nurse practitioners, physician assistants). Other healthcare professionals such as dietitians, nurses, and psychologists were excluded from

this survey as well as clinicians who answered that their practice does not include caring for patients with CeD.

2.2 | Survey instrument

A subcommittee of the NASPGHAN Celiac Disease Special Interest Group (SIG) was formed to develop a "State of Celiac Disease" survey to examine current practice patterns and training in North America, and to identify gaps in care and opportunities for improvement. The survey content was reviewed by members of the Celiac Disease SIG for readability and face validity, with feedback incorporated into the final instrument that was approved by the NASPGHAN Survey Task Force.

The 23-item online survey (Supporting Information File 2) explored four themes: (1) screening and diagnosis, both before and after the COVID-19 pandemic; (2) CeD monitoring, resources (i.e., dietitian, psychologist), and treatment; (3) family screening and transition of care; and (4) CeD focused training.

Specific questions probing practice patterns related to use of serology, models of care, gluten-free dietary education, long-term clinical monitoring, and practice adaptations in response to the COVID-19 pandemic. Information regarding provider type, experience level, practice setting, and affiliation with a designated CeD center were all collected to better understand variability in CeD care.

2.3 | Data collection & analysis

NASPGHAN distributed the survey via email to all active members beginning in September 2021 with monthly reminder emails sent during the data collection period. Survey data was collected using the Alchemer web survey platform (Alchemer). To maximize response rates, the survey used a respondent-friendly design with understandable language. Only data from respondents who met inclusion and exclusion criteria and completed the entire survey were analyzed.

Statistical analysis comprised of descriptive statistics, percentages, and comparisons using R software (version 4.1.2). Differences between groups were compared using Student's *t*-test, with a two-sided p value < 0.05 considered significant.

3 | RESULTS

Data were collected and analyzed from 278 completed surveys—a response rate of 10.8% (278/2552). Most respondents practiced in the United States (89.9%, $n = 250$) and Canada (8.6%, $n = 24$), with 0.7% from Mexico ($n = 2$) or unknown ($n = 2$). Although the total number of Canadian respondents was less than the US, the response rate was higher. Table 1 characterizes the study population, including level of training, practice model, affiliation with a CeD center, and number of patients with CeD treated in the past year.

TABLE 1 Characteristics of respondents that completed NASPGHAN State of Celiac Disease Survey.

NASPGHAN survey respondent demographics
Country of practice
United States: 250 (89.9%)
Canada: 24 (8.6%)
Mexico: 2 (0.7%)
Declined to answer: 2 (0.7%)
Provider type
Fellow/trainee: 18 (6.5%)
Nurse practitioner/physician assistant: 27 (9.7%)
Junior or midlevel attending (0–10 years of practice): 99 (35.6%)
Senior attending (>10 years of practice): 134 (48.2%)
Practice setting
Private practice: 22 (7.7%)
Academic medical center (urban area): 212 (73.9%)
Academic medical center (rural area): 16 (5.7%)
Community hospital (urban area): 28 (10.3%)
Community hospital (rural area): 7 (2.5%)
Practice or medical center affiliated with celiac center
Yes: 122 (43.9%)
No: 156 (56.1%)
Provider clinical experience with celiac disease
1–10 celiac cases/year: 108 (38.9%)
11–20 celiac cases/year: 81 (29.1%)
21–50 celiac cases/year: 51 (18.3%)
51–100 celiac cases/year: 21 (7.6%)
>100 celiac cases/year: 15 (5.4%)
Declined to answer: 2 (0.7%)

Abbreviation: NASPGHAN, North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition.

3.1 | Screening and diagnosis

All 278 respondents (100%) used anti-tissue transglutaminase-immunoglobulin A (TTG-IgA) as the initial screening test in children for CeD, and most (92.4%) also assessed total IgA. Additional celiac serologies, such as deamidated gliadin (DGP) IgG

(10.8%, 30/278), DGP IgA (10.1%, 28/278), and endomysial antibody (EMA) IgA (15.0%, 41/278) and EMA IgG (0.7%, 2/278), were utilized in the initial screen by a subset of providers. Clinical experience with CeD did not impact serology screening practices, as those with a smaller CeD practices (1–20 patients per year) used non-TTG IgA serologies 14.3% (27/189) of the time versus 16.1% (14/87) for providers with >20 cases/year ($p = 0.35$).

All respondents reported using endoscopy with intestinal biopsy for the diagnosis of CeD, with 47.5% (132/278) of providers also accepting non-biopsy, serology-based criteria for diagnosis in certain circumstances (Figure 1). A higher proportion of respondents from Canada (54.2%, 13/24) compared to the US (39.6%, 99/250) follow the revised ESPGHAN 2020 guidelines of serology-based diagnosis,[5] although this difference was not significant ($p = 0.08$). Providers at community hospitals (51.7%, 15/29) and private practice (47.1%, 8/17) appear to use ESPGHAN 2012 guidelines (serologic diagnosis in symptomatic children plus HLADQ2/8 genotyping)[7] at a higher proportion than clinicians at solely academic centers (39.3%, 86/219), although this did not calculate a statistical significance ($p = 0.1$). For patients that did not meet the serology-based diagnostic criteria outlined in ESPGHAN guidelines, a "diagnosis" of CeD without biopsy was made more commonly by those not affiliated with a CeD center (28.2%, 44/156), than those who were (16.4%, 20/122, $p < 0.05$).

The wait times for pediatric gastroenterology consultation and endoscopy procedures in children with suspected CeD varied by country and practice; 70.0% of US providers (175/250) state the average wait time was within 30 days while only 45.8% (11/24) of Canadians reported this average wait time. Those in private practice had the shortest wait times, with 58.3% (10/17) reporting seeing consultations within 2 weeks. The average wait time from gastrointestinal (GI) consultation to endoscopy was shorter in the United States as 80.0% (200/250) of respondents were able to obtain a biopsy in less than 30 days of consultation versus 20.8% (5/24) in Canada ($p < 0.05$).

Clinical practice guidelines recommend obtaining 5–6 duodenal biopsies during the endoscopy for suspected CeD: 1–2 biopsies from the duodenal bulb and ≥4 from the distal duodenum.[5,6] The majority of respondents reported taking five or more duodenal biopsies. No significant differences in biopsy practice patterns (i.e., number of total duodenal biopsies and if bulb biopsies were taken) were found between country, years in practice or affiliation with a CeD center, although it is still notable that 11.5% (32/278) of respondents reported taking four or fewer biopsies and 3.2% (9/278) do not regularly biopsy the duodenal bulb in suspected CeD. The majority of respondents who collect bulb biopsy reported placing it in a separate specimen container (58.2%, 128/220).

Given the timing of this survey, changes in diagnostic practice related to the COVID-19 pandemic were analyzed. The number of respondents who considered a non-biopsy serology-based approach to

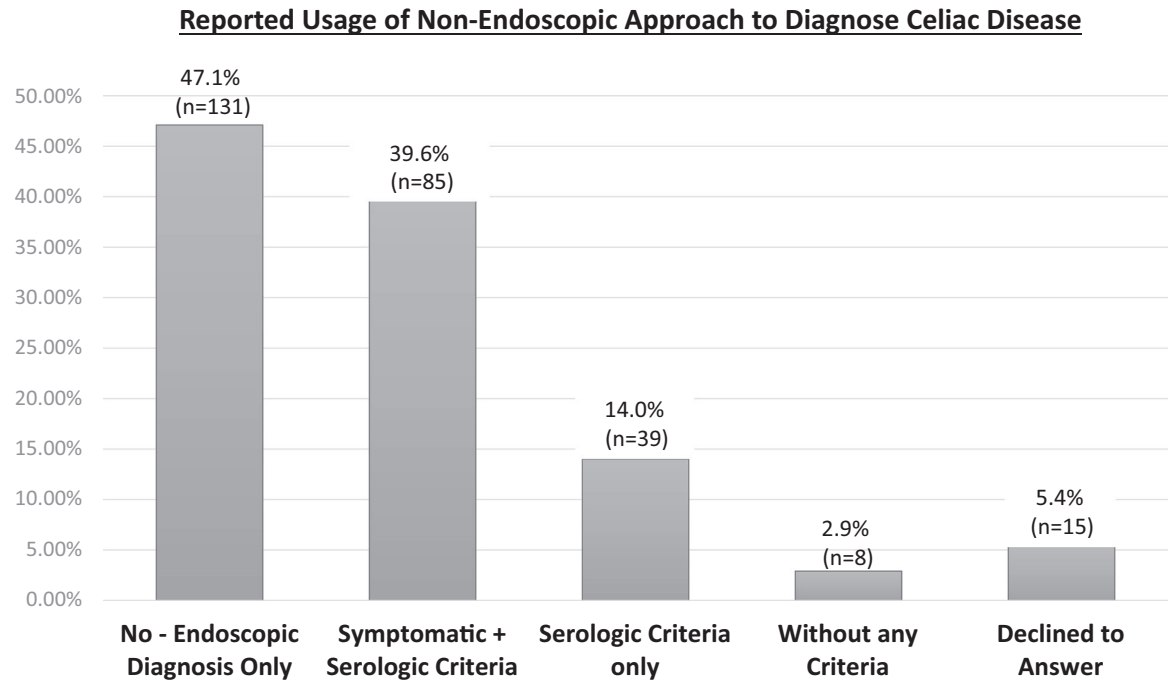

FIGURE 1 Responses to survey question "Do you offer non-endoscopic diagnosis of celiac disease?"

CeD diagnosis increased during the COVID-19 pandemic. Overall, 37.4% (104/278) of providers changed their approach to accept non-biopsy, serology-based diagnosis in lieu of endoscopy. This was particularly offered to symptomatic patients and/or those who met certain serology-based criteria (i.e., ESPGHAN guidelines). Canadian providers were more accepting of a non-biopsy, serology-based diagnosis during the pandemic compared to US providers (73% vs. 32%, $p < 0.05$), as were providers at academic centers compared to respondents practicing in community-hospitals (29% vs. 16%, $p = 0.04$). Common reasons for forgoing endoscopy during the pandemic included: family request (65/104, 62.5%), publication of ESPGHAN 2020 guidelines (63/104, 60.5%), decreased availability of endoscopy services (33/104, 31.7%), concern of COVID-19 transmission through anesthesia/procedure (18/104, 17.3%), and patients already consuming a gluten-free diet by the time of consultation (16/104, 15.4%).

3.2 | Treatment and monitoring after the diagnosis

CeD treatment centers on effective gluten-free dietary education and monitoring for nutritional deficiencies, anemia, endocrine disorders, hepatic dysfunction, and bone disease.[3,8]

Survey respondents acknowledged the most commonly ordered tests after CeD diagnosis were complete blood count (89.3%), vitamin D 25-OH (92.5%), and thyroid function tests (80.2%), followed by iron studies (70.8%) and folate (23.7%). In addition to labs, dual energy X-ray absorptiometry (DEXA) scans to assess bone density were ordered after CeD diagnosis by 15.8.% (44/278) of providers, most of whom (63.6%, 28/44) were affiliated with a CeD center.

When asked how patients are provided education regarding the gluten free diet, recommended websites (56.8%), dietitian teaching (46.7%), and written materials (42.1%) were most often utilized, with multiple interventions available for those affiliated with a CeD center. The most frequently reported barriers to providing dietitian support and education were cost and lack of insurance coverage (Table 2).

Ambulatory GI and dietitian appointments after CeD diagnosis are integral to dietary surveillance and patient success. In this survey, 68.3% (190/278) of respondents advised their patients to be seen 3 months after the diagnosis, with 25.1% (70/278) extending out to 6 months, and 1.8% in 1 year (5/278).

Most respondents (91.0%, 253/278) routinely monitor TTG IgA as part of CeD surveillance in patients on a gluten-free diet. A small number of providers routinely follow other serologies including DGP IgA (6.5%, 18/278), DGP IgG (7.2%, 20/278), EMA (10.1%, 28/278), and TTG IgG (6.1%, 17/278). Respondents at institutions with a CeD center did not differ significantly in their lab ordering practices. Other laboratory tests ordered routinely during follow-up were vitamin D (25-OH) (71.9%, 200/278), complete blood count (68.3%, 190/278), thyroid function tests (57.9%, 161/278), liver transaminases (53.2%, 148/278), and iron studies (47.8%, 133/278). Uncommon studies were hemoglobin A1C (11.5%, 32/278), zinc (10.8%, 30/278), folate (16.9%, 47/278), thyroid peroxidase antibody (2.5%, 7/278), and DEXA scans (5.8%, 16/278), respectively (Table 3).

Repeat endoscopy and duodenal biopsy in CeD surveillance were utilized primarily in cases with persistent gastrointestinal symptoms (91.0%, 253/278) or persistently positive celiac serologies (67.6%, 188/278). Concern regarding dietary adherence was another common reason for endoscopy (21.5%, 61/278). Notably 25 (8.7%) survey respondents

TABLE 2 Survey responses on patient and provider gluten-free diet education opportunities and barriers.

Are there barriers to accessing nutritional counseling/registered dietitian	**Number of responses (%) *N* = 181**
No, we have an available dietitian affiliated with our practice or in the community	98 (54.1%)
Yes, barrier of cost and/or lack of insurance coverage for dietitian appointment	50 (27.6%)
Yes, available qualified/knowledgeable dietitian resources are in my community, but inadequate to meet demand	15 (8.3%)
Yes, families are not interested in seeing a dietitian	10 (5.5%)
Yes, lack of available dietitian knowledgeable in celiac disease in my area	8 (4.4%)
How are we teaching about celiac disease & the gluten-free diet	**Number of responses (%) *N* = 197**
Self-learning	
– Recommend website	112 (56.8%)
– Written materials (celiac disease overview, grocery store visit guide, etc.)	83 (42.1%)
– E-learning modules	4 (2.0%)
Teaching	
– Consult to registered dietitian/nutritionist	92 (46.7%)
– Clinician (MD/DO/APP): one-on-one teaching in clinic	49 (24.9%)
– Refer to local support group to provide education	22 (11.2%)
– Group education virtually	10 (5.1%)
– Nurse (RN): one-on-one teaching	5 (2.5%)
Other	13 (6.6%)

Abbreviations: AAP, advanced practice providers; MD/DO, physicians; RN, registered nurse.

TABLE 3 Provider practice patterns of laboratory and radiology tests at celiac disease diagnosis versus routine follow-up.

Test name	At celiac diagnosis	Routine follow-up
Total immunoglobulin A	–	24.1%
TTG IgA	–	91.0%
TTG IgG	–	6.1%
Deamidated gliadin IgA (DGP IgA)	–	6.5%
DGP IgG	–	7.2%
EMA	–	11.1%
Complete blood count	89.3%	68.3%
Liver enzymes (aspartate and alanine aminotransferases)	75.1%	53.2%
Thyroid function tests (TSH, T4)	80.2%	57.9%
Thyroid peroxidase antibody	6.7%	2.5%
Hemoglobin A1c	16.6%	11.5%
Vitamin D	92.5%	71.9%
Iron studies	70.8%	47.8%
Zinc	15.8%	10.8%
Folate	23.7%	16.9%
Hepatitis B serology	36.0%	–
HLA DQ2/DQ8 genotyping	5.1%	–
DEXA bone scan	15.8%	5.8%
Other	7.5%	6.7%

Abbreviations: EMA, endomysial antibody; DEXA, dual energy X-ray absorptiometry; DGP IgG, deamidated gliadin IgG; HLA, human leukocyte antigen; TTG-IgA, tissue transglutaminase IgA; TTG-IgG, tissue transglutaminase IgG.

routinely recommend follow-up endoscopy as part of disease monitoring after at least 1–2 years on the gluten-free diet.

3.3 | Family screening and transition

It is known that first degree relatives of patients with CeD are at increased risk of developing CeD.[9,10] The majority of respondents 249/278 (89.6%) recommend screening all first degree relatives for CeD, however, there was a lack of consensus regarding screening frequency: 145 (52.2%) screen once, whereas 104 respondents (37.4%) recommend screening at intervals ranging from 1 to 5 years until puberty or through adulthood. Some providers (9.7%, 27/278) recommend that only symptomatic first-degree relatives be screened and 0.7% do not routinely recommend family screening.

Structured and planned transition of care of children with CeD to adult providers is recommended.[11,12] In our survey, 84.9% (236/278) were involved in transition of care. Most often, respondents transitioned their patients to adult gastroenterologists (182/278, 65.4%), of which 11.6% (21/182) were at adult GI CeD centers. A small, but notable proportion of respondents transitioned patients to a general practitioner (50/278, 18.0%).

3.4 | CeD training

The majority (192/278, 69.1%) of providers reported receiving no additional specialty training on CeD outside of their general GI curriculum. Despite a large proportion of respondents being affiliated with a CeD center (43.9%, 121/278) and 18 pediatric GI trainees (6.5%, 18/278) participating in the survey, professional development opportunities related to CeD during fellowship were underwhelming. Only 26.2% (73/278) reported receiving specialized CeD education during their training years (e.g., lectures, e-curriculum, conference), 23.7% (66/278) shadowed or worked in CeD clinic, and 6.1% (17/278) conducted celiac-focused research.

4 | DISCUSSION

This survey reveals the heterogeneity of provider-reported practices for the diagnosis and management of CeD in children in North America. While the majority of providers use TTG IgA and total IgA to screen for CeD, consistent with pediatric and adult guidelines, a substantial number reported using DGP and EMA. Additional education and cost effectiveness studies could reinforce the use of CeD diagnostic algorithms and decrease use of panels and subsequent evaluations with low likelihood of diagnosing CeD.

Although endoscopy remains the standard, 47.5% of respondents reported using serologic criteria to diagnose CeD without a biopsy, and frequency of this practice increased after COVID-19 pandemic affected access to specialists, availability of endoscopy and family hesitation to the procedure. As one respondent noted, “COVID forced more of us to rethink this practice.” However, there is controversy regarding the applicability of ESPGHAN non-biopsy diagnostic criteria[5,7] to North America populations where different TTG IgA assays are used and the predominant wheat varieties differ from those in Europe.[13] Further studies are needed in North America on the accuracy of serology-based diagnosis of CeD and diagnosis of CeD based on results of screening tests that do not meet specified criteria without involvement of a gastroenterologist or clinician with expertise in CeD.

CeD is a chronic condition which requires ongoing follow-up irrespective of how the diagnosis is confirmed. Strikingly, nearly 90% of respondents routinely order TTG IgA during follow-up even though it has poor sensitivity for persistent mucosal damage and is not Food and Drug Administration (FDA) approved for this indication.[14,15] It is unclear whether respondents routinely order additional markers such as TTG IgG, DGP IgG, and EMA in routine follow-up intentionally or if this is an unintended consequence of celiac laboratory panels developed for initial screening being applied to follow-up. The role of follow-up biopsy, whether by traditional oral route or the rapidly emerging unsedated transnasal endoscopy technique will need further study.

Recommended surveillance includes annual complete blood count, thyroid function tests, vitamin D (25-OH), liver function testing, and iron studies, but with nearly one of every three respondents not recommending these tests annually (vitamin D 25-OH highest at 71.9% with iron studies only completed by 47.8%), the cost effectiveness of this practice may need to be reexamined. Similarly, DEXA scans—conducted by 15% of providers—may be more beneficial if reserved for those with severe malabsorption, prolonged delay in diagnosis or a presentation suspicious of bone disease with fractures.[8,16] Educational initiatives will also be key to judicious clinical testing of vitamins and micronutrients[17] (e.g., folate, zinc, vitamin B12) following an adequate clinical and dietary assessment.

While the United States Preventive Services Task Force in 2017 found inadequate evidence to screen asymptomatic family members, pediatric experts have promoted targeted screening.[3,18] Most NASPGHAN respondents are screening first-degree relatives, although there is variability in the frequency and age cut-off for testing. Additional research is needed to determine optimal screening strategies.

A recent study of pediatric celiac follow-up practices across Europe identified a major deficiency in transition to adult care.[19] Although the majority of survey respondents report involvement in transition of care, this survey did not examine the availability of celiac centers that treat adults. Close collaboration between pediatric and adult GI providers has been highlighted as important but may not be available so that follow-up is at the discretion of the primary care physician.[20,21]

Education of physicians was highlighted in other physician-based surveys as a key recommendation to improve outcomes in the care of CeD. These education concerns were supported by the National Institute of Health in 2004, which stressed the importance of CeD awareness and role of educating a broad range of healthcare providers.[22] Despite the high incidence of CeD, physician education of CeD has often been described to be lacking in family practice, internal medicine and general pediatrics.[23] Our study highlights lack of pediatric GI fellowship training in CeD. The majority of respondents endorsed receiving little didactic CeD teaching and few fellowship programs seem to offer or require participation in CeD subspecialty clinic. Although clinical experience may not always be available, education and collaboration are attainable with the development of CeD curricula and a CeD consortium for pediatricians, gastroenterologists, and other specialists to participate in quality improvement and research. In North America, certificates of training exist for registered dietitians in the care of CeD, but no similar model has yet been developed for physicians. Continuing medical education opportunities through CeD centers, pilot grants, and international conferences which focus on CeD research need to be promoted to recruit bright young minds to the field.[24]

CeD is a chronic condition that has gastrointestinal, nutritional, financial, and psychosocial ramifications. In this survey, common barriers to care included wait times for GI consultation and/or endoscopy, dietitian support, and limited educational resources. The COVID-19 pandemic influenced CeD practice patterns, and brought its own hurdles, but it also pushed new technologic advancements (i.e., telehealth) that may be useful to promote a more unified pediatric CeD care network. These survey results on care and educational practices highlight potential avenues for improving health outcomes. Future research priorities and CeD guidelines should take into account these variable practices and barriers.

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CONFLICT OF INTEREST STATEMENT

Dr. Jocelyn Silvester has served on advisory boards for Alimentiv, Mozart Therapeutics, Takeda Pharmaceuticals, and Teva Pharmaceuticals. She has served as site-PI for clinical trials sponsored by Cour Pharmaceuticals and Takeda Pharmaceuticals and has research support from Milky Way Life Sciences. Research reported in this publication was supported by the National Institute Of Diabetes And Digestive And Kidney Diseases of the National Institutes of Health under Award Number K23DK119584. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The remaining authors declare no conflict of interest.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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