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Challenges and opportunities in the multidisciplinary management of celiac disease in the United States: results of a case-based survey

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Introduction

- Celiac disease (CeD) is an immune-mediated condition characterized by inflammation of the small intestine and is triggered by gluten ingestion in genetically predisposed individuals.¹
- Current management of CeD is strict lifelong adherence to a gluten-free diet (GFD).²
- Diagnosis and patient management after diagnosis are varied and often suboptimal, and inadequate follow-up and ongoing symptoms can affect patient health-related quality of life.^{3,4}
- We evaluated practice patterns and educational needs among healthcare professionals (HCPs) in the USA who manage patients with CeD.

Methods

- A survey was conducted from August to September 2023 among HCPs who treat patients with CeD.
 - Participating HCPs included gastroenterologists (GEs), primary care physicians (PCPs), GE- and PCP-associated nurse practitioners (NPs) and physician associates (PAs), and dietitians.
- The survey included questions based on a simulated patient case to help to provide context for diagnosis and subsequent decision-making, as well as questions on CeD treatment pathways and practice patterns.

Results

- In total, 303 HCPs participated in the survey and the majority (67%) treated 1 to 5 patients with CeD each month (Table 1).
- Recommended laboratory diagnostic tests for CeD varied by specialty, the most common are included below.

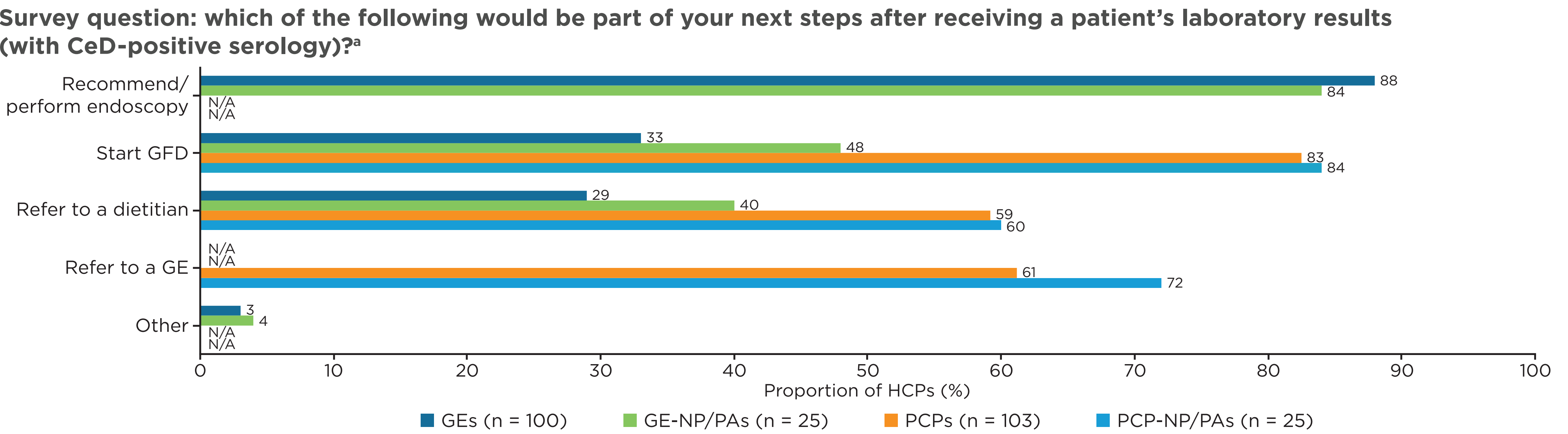
Table 1. Demographics of participating HCPs

Demographic	GE	GE-NP/PA	PCP	PCP-NP/PA	Dietitian	Total
N	100	25	103	25	50	303
Race/ethnicity,* n (%)						
White	55 (55)	18 (72)	65 (63)	21 (84)	44 (88)	203 (67)
Asian	30 (30)	3 (12)	24 (23)	1 (4)	2 (4)	60 (20)
Black/African American	2 (2)	2 (8)	3 (3)	3 (12)	0 (0)	10 (3)
Other ^b	16 (16)	2 (8)	11 (11)	0	4 (8)	33 (11)
Practice location, n (%)						
Urban	46 (46)	12 (48)	29 (28)	6 (24)	17 (34)	110 (36)
Suburban	47 (47)	12 (48)	61 (59)	13 (52)	25 (50)	158 (52)
Rural	6 (6)	1 (4)	13 (13)	6 (24)	8 (16)	34 (11)
Did not answer	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0)
Practice type, n (%)						
Academic/university hospital/medical school	22 (22)	7 (28)	2 (2)	3 (12)	1 (2)	35 (12)
Community hospital	6 (6)	1 (4)	2 (2)	1 (4)	0 (0)	10 (3)
Multi-specialty group practice	14 (14)	4 (16)	28 (27)	7 (28)	0 (0)	53 (17)
Single-specialty group practice	38 (38)	11 (44)	35 (34)	9 (36)	34 (68) ^c	127 (42)
CeD patients/month, n (%)						
1-5	58 (58)	12 (48)	72 (70)	18 (72)	44 (88)	204 (67)
6-10	23 (23)	10 (40)	16 (16)	6 (24)	2 (4)	57 (19)
11-15	9 (9)	1 (4)	7 (7)	1 (4)	3 (6)	21 (7)
>15	10 (10)	1 (4)	8 (8)	1 (4)	1 (2)	21 (7)

*Respondents could select more than one option. ^bOther included native Hawaiian/Pacific Islander, mixed race, Hispanic, Indian subcontinent, Italian American, and 'prefer not to say'. ^cPrivate practice for dietitians (single- or multi-specialty status not recorded).

CeD, celiac disease; GE, gastroenterologist; HCP, healthcare professional; NP, nurse practitioner; PA, physician associate; PCP, primary care physician.

Figure 1. The majority of PCPs would refer a patient to a GE and/or dietitian and recommend a GFD after a CeD-positive serology test, whereas fewer GEs would refer to a dietitian or recommend a GFD as the next step



^aN/A indicates when a question was not presented to a specific HCP specialty.

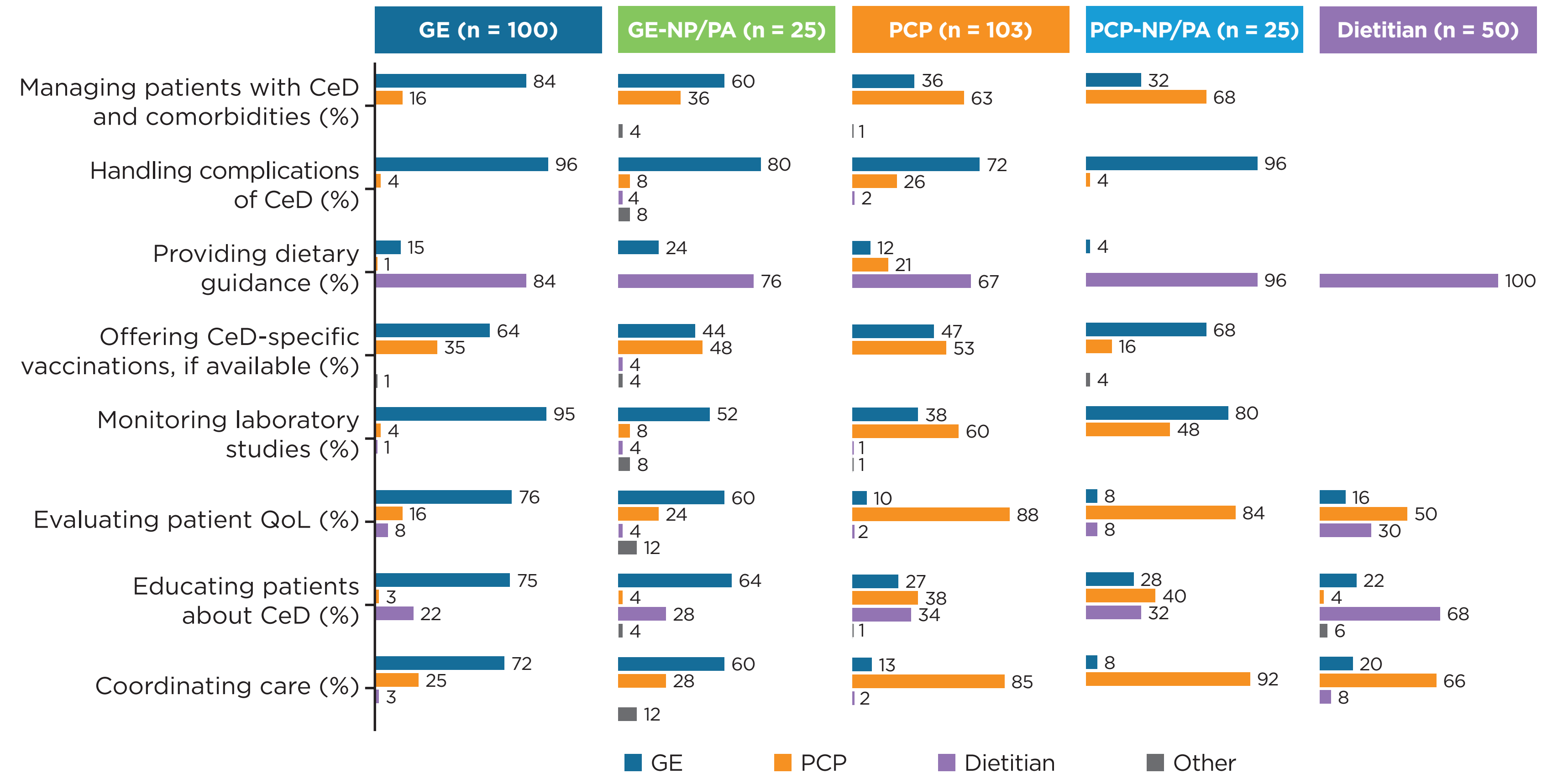
CeD, celiac disease; GE, gastroenterologist; GFD, gluten-free diet; HCP, healthcare professional; NP, nurse practitioner; PA, physician associate; PCP, primary care physician.

Key messages

- A survey of US healthcare professionals revealed educational needs regarding the diagnosis and management of patients with celiac disease (CeD) and variability in practice patterns.
- Further education on key indications for CeD testing, optimal diagnostic pathways, complications associated with untreated CeD, and the need for ongoing patient monitoring may optimize disease management and improve outcomes for patients with CeD.

Figure 2. HCP specialties responsible for coordinating specific aspects of care and education for patients with CeD vary across practices

Survey question: for a patient in your practice with CeD, who would be primarily responsible for the following aspects of patient care?



CeD, celiac disease; GE, gastroenterologist; HCP, healthcare professional; NP, nurse practitioner; PA, physician associate; PCP, primary care physician; QoL, quality of life.

Conclusions

- Many aspects of the diagnosis and management of patients with CeD vary between different HCP specialties in the USA and not all HCPs follow ACG recommendations.
- Education is needed to improve diagnosis rates and optimize outcomes for these patients.

Presented at Digestive Disease Week (DDW) 2025, May 3-6, 2025, San Diego, CA, USA

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Figure 3. Lower proportions of PCPs and PCP-NP/PAs are comfortable with various aspects of managing patients with CeD than GEs and GE-NP/PAs

Survey question: how comfortable are you with each of the following aspects of managing patients with CeD? (Figure shows proportion who responded 'very' or 'extremely' comfortable)

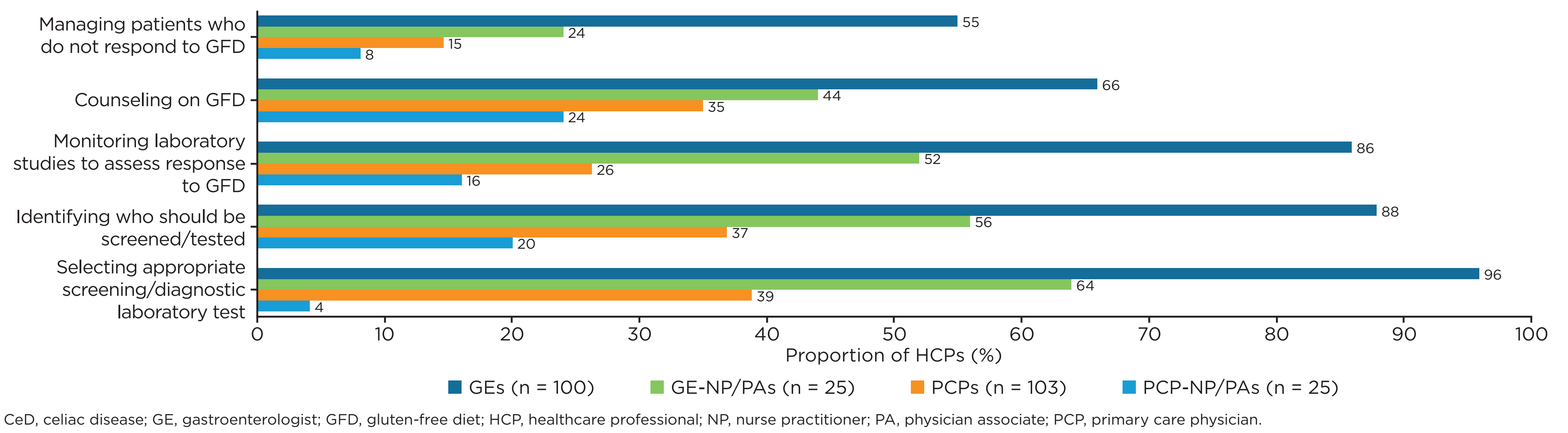


Figure 4. During the first year after CeD diagnosis, most HCPs ask patients about adherence to a GFD 3-4 times and assess quality of life informally 2-4 times; however, validated tools to assess quality of life are not often used and not all HCPs refer patients for a bone density scan

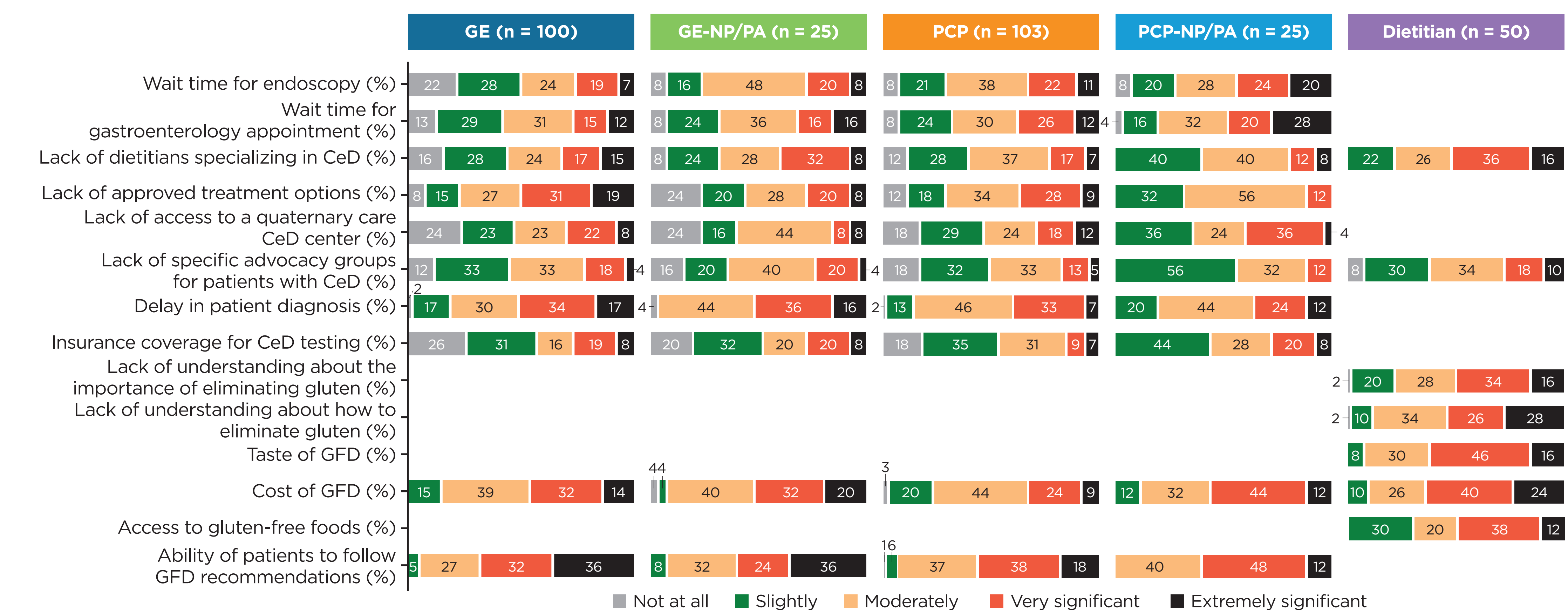
Survey question: when managing patients with CeD in the first year after diagnosis, how often do you perform the following assessments?



CD-QoL, Celiac Disease Quality of Life Measure; CeD, celiac disease; DEXA, dual-energy X-ray absorptiometry (bone density scan); GE, gastroenterologist; GFD, gluten-free diet; HCP, healthcare professional; NP, nurse practitioner; PA, physician associate; PCP, primary care physician; QoL, quality of life.

Figure 5. According to HCPs, the most common significant barriers to optimal care for patients with CeD are the ability of patients to follow a GFD and diagnosis delays, whereas according to dietitians, the cost, taste, and access to gluten-free foods, and lack of patient understanding of how to avoid gluten are significant barriers

Survey question: how significant are the following barriers to the optimal management of your patients with CeD?^a



^aQuestions to dietitians were different from those presented to the other HCPs.

CeD, celiac disease; GE, gastroenterologist; GFD, gluten-free diet; HCP, healthcare professional; NP, nurse practitioner; PA, physician associate; PCP, primary care physician.

Abbreviations

ACG, American College of Gastroenterology; CD-QoL, Celiac Disease Quality of Life Measure; CeD, celiac disease; DEXA, dual-energy X-ray absorptiometry (bone density scan); GE, gastroenterologist; GFD, gluten-free diet; HCP, healthcare professional; NP, nurse practitioner; PA, physician associate; PCP, primary care physician; QoL, quality of life.

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Funding statement

This study was sponsored by Takeda Development Center Americas, Inc. Medical writing support was provided by Giovanni Ferrari, PhD, and Ify Achebe, MSc, of Oxford PharmaGenesis, Oxford, UK and was funded by Takeda Pharmaceuticals.

Disclosures

SC and AS are employees of Takeda Pharmaceuticals USA, Inc. and receive stock or stock options. DAL and NC are employees of Takeda Development Center Americas, Inc. and receive stock or stock options. GS and AR are employees of CE Outcomes LLC, and ML is a contractor for CE Outcomes LLC, who were funded by Takeda for the conduct of this study.