

Rates of biopsy-confirmed celiac disease diagnosis and gluten-free diet adherence in Europe and the United States: a real-world survey

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BACKGROUND

- Guidelines recommend that celiac disease (CeD) in adults is confirmed by biopsy¹⁻² and managed with a gluten-free diet (GFD).
- However, existing data on biopsy-confirmed (BC) diagnosis rates and GFD-adherence across countries are limited.

OBJECTIVE

To identify differences in rates of biopsy-confirmed diagnosis of CeD and GFD-adherence across Germany, Italy, Spain, and the United States (US).

METHODS

- Data were drawn from the Adelphi Real World CeD Disease Specific Programme (DSP)TM, a cross-sectional survey with retrospective data collection of physicians and their patients with CeD, conducted in Germany, Italy, Spain, and the US between July 2021 and January 2022. The DSP methodology has been previously published and validated³⁻⁵.
- Gastroenterologists (GIs) and primary care physicians (PCPs) were recruited to complete patient record forms for their next eight consecutively consulting adult CeD patients who were symptomatic in the last 12 months.

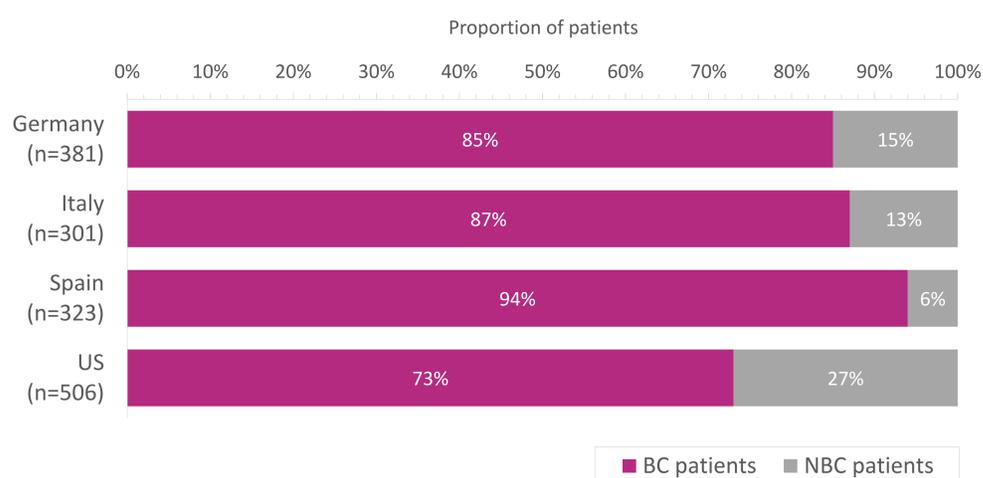
- GIs and PCPs reported demographics, diagnostic tests used, and GFD-adherence immediately after diagnosis for their patients.
- The same patients were invited to complete a voluntary patient self-completion form which captured consultation history and awareness of CeD prior to diagnosis.
- Patients were grouped according to their diagnosis: BC or non-biopsy-confirmed (NBC).
- Analyses were descriptive.

RESULTS

- Analyses included data from 262 GIs and PCPs and 1,511 patients from Germany (n=381), Italy (n=301), Spain (n=323), and the US (n=506).
- BC diagnosis rates were 85% of patients (Germany), 87% (Italy), 94% (Spain), and 73% (US), with the remainder NBC (**Figure 1**).

- On average, patients had been diagnosed with CeD for more than 2 years regardless of the use of a biopsy. Average disease duration was notably short in the US (median {IQR} 2.1 {0.9-4.4} years for BC; 2.3 {0.8-5.3} years for NBC patients; **Table 1**).

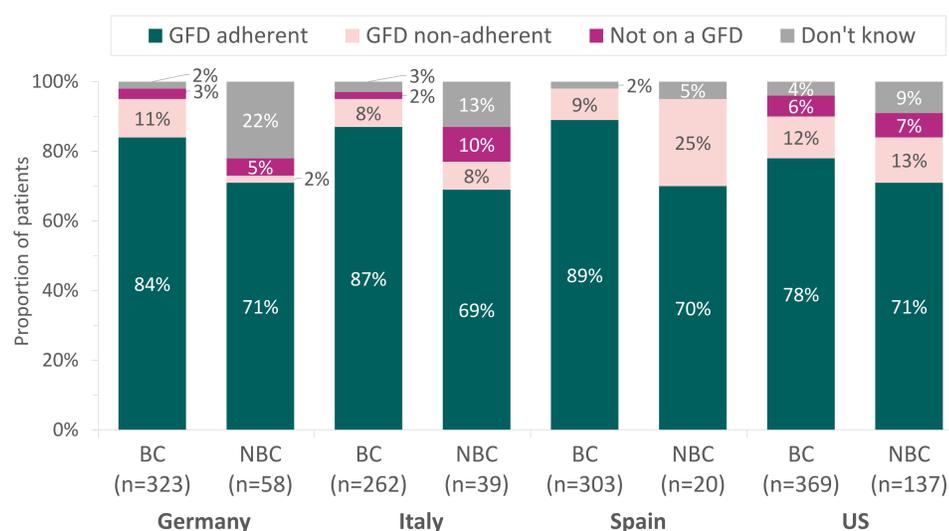
Figure 1. Patient diagnosis using biopsy by country



BC, Biopsy-confirmed; NBC, Non-biopsy confirmed; US, United States

- Overall, patients had a mean [standard deviation; SD] age of 37.4 [13.1] years. Patient age split by countries and cohort is shown in **Table 1**.
- The proportion of female patients was 60–87% across the countries and BC/NBC cohorts, except for NBC patients in Germany of which 38% were female (**Table 1**).
- Mean [SD] BMI ranged from 21.8 [2.6] in Italy to 7.3 [4.8] in the US, most patients were White (92%), and 46–74% of patients were in full-time work (**Table 1**).

Figure 2. Physician-reported gluten-free diet adherence immediately after diagnosis



BC, Biopsy-confirmed; GFD, Gluten-free diet; NBC, Non-biopsy confirmed; US, United States.

'Gluten-free diet adherent' combines response options: 'On a strict gluten-free diet with no gluten uptake' and 'On a gluten-free diet, but likely to have inadvertent gluten uptake.' 'Gluten-free diet non-adherent' combines response options: 'On a gluten-free diet, but likely to have inadvertent gluten uptake occasionally' and 'On a gluten-free diet, but likely to have inadvertent gluten uptake most of the time.'

- Across all countries, GFD-adherence was 78–89% among BC patients and 69–71% among NBC patients (**Figure 2**).
- GFD-adherence was unknown for between 2–4% of BC patients, compared to 5–22% of NBC patients (**Figure 2**).

Table 1. Patient demographics and characteristics

	n	Germany		Italy		Spain		US	
		BC	NBC	BC	NBC	BC	NBC	BC	NBC
Age, mean [SD]		34.5 [11.0]	35.2 [10.9]	38.2 [13.4]	36.0 [14.0]	38.6 [13.4]	34.8 [12.7]	38.0 [14.2]	40.4 [13.0]
Female, n (%)		195 (60)	22 (38)	157 (60)	34 (87)	195 (64)	15 (75)	227 (62)	87 (64)
BMI, mean [SD]		23.1 [2.9]	23.2 [2.9]	23.1 [3.7]	21.8 [2.6]	23.4 [3.3]	23.2 [3.1]	25.0 [4.6]	27.3 [4.8]
Ethnicity, White, n (%)		310 (96)	52 (90)	248 (95)	35 (90)	288 (95)	20 (100)	307 (83)	124 (91)
Working full-time, n (%)		205 (63)	42 (72)	161 (61)	18 (46)	144 (48)	12 (60)	210 (57)	102 (74)
Disease duration, Years, median [IQR]		2.1 [0.9–4.0]	3.9 [0.9–12.1]	3.5 [1.2–8.6]	6.6 [1.5–10.7]	3.5 [1.8–6.7]	3.1 [0.5–8.5]	2.1 [0.9–4.4]	2.3 [0.8–5.3]

Patients with known data. BC, Biopsy-confirmed; BMI, Body mass index; IQR, Inter-quartile range; NBC, Non-biopsy confirmed; SD, Standard deviation; US, United States

DISCLOSURES

HK, NH, FD & RL are employees of Adelphi Real World. VB, MG & MG are employees of the Celiac Disease Foundation.

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CONCLUSIONS

- We found that not all patients had a BC diagnosis of CeD, notably in the US.
- Across countries, 69–71% of NBC patients were GFD-adherent, compared to 78–89% of BC patients.
- GFD status was unknown mainly in NBC patients, suggesting less engagement in condition management.
- Further analysis is needed to investigate the association of BC diagnosis with GFD-adherence and ultimately optimal disease control, alongside understanding reasons for using/not using biopsy for diagnosing CeD.