

## Partner Burden: A Common Entity in Celiac Disease

Abhik Roy<sup>1</sup> · Maria Minaya<sup>1</sup> · Milka Monegro<sup>1</sup> · Jude Fleming<sup>1</sup> · Reuben K. Wong<sup>2,3</sup> · Suzanne Lewis<sup>1</sup> · Benjamin Lebwohl<sup>1</sup> · Peter H. R. Green<sup>1</sup>

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### Abstract

**Background** Caregiver burden is documented in several chronic diseases, but it has not been investigated in celiac disease (CD).

**Aims** We aim to quantify the burden to partners of CD patients and identify factors that affect the perceived burden.

**Methods** We surveyed patients with biopsy-proven CD and their partners. Patients completed CD-specific questions, including the validated Celiac Symptom Index (CSI) survey. Partners completed the validated Zarit Burden Interview (ZBI) and questions regarding sexual and relationship satisfaction. Univariable and multivariable analyses were used to assess the association between demographics, CD characteristics, and partner burden.

**Results** In total, 94 patient/partner pairs were studied. Fifteen patients (16 %) reported a CSI score associated with a poor quality of life, and 34 partners (37 %) reported a ZBI score corresponding to mild-to-moderate burden. Twenty-two partners (23 %) reported moderate-to-low overall relationship satisfaction, and 12 (14 %) reported moderate-to-low sexual satisfaction. The degree of partner burden was directly correlated with patient CSI score

( $r = 0.27$ ;  $p = 0.008$ ), and there were moderate-to-strong inverse relationships between partners' burden and relationship quality ( $r = -0.70$ ;  $p < 0.001$ ) and sexual satisfaction ( $r = -0.42$ ;  $p < 0.001$ ). On multivariable logistic regression, predictors of mild-to-moderate partner burden were low partner relationship satisfaction (OR 17.06, 95 % CI 2.88–101.09,  $p = 0.002$ ) and relationship duration  $\geq 10$  years (OR 14.42, 95 % CI 1.69–123.84,  $p = 0.02$ ).

**Conclusions** Partner burden is common in CD, with more than one-third of partners experiencing mild-to-moderate burden. Partner burden is directly correlated with patient symptom severity, and it increases with poorer sexual and relationship satisfaction. Healthcare providers should address relationship factors in their care of patients with CD.

**Keywords** Celiac disease · Burden of illness · Symptom assessment · Marital relationship

### Abbreviations

IBS	Irritable bowel syndrome
CD	Celiac disease
GFD	Gluten-free diet
CSI	Celiac Symptom Index
RS	Relationship Scale
ZBI	Zarit Burden Interview

✉ Peter H. R. Green  
pg11@cumc.columbia.edu

<sup>1</sup> Department of Medicine, Celiac Disease Center, Columbia University College of Physicians and Surgeons, Columbia University Medical Center, Harkness Pavilion, 180 Fort Washington Ave, Room 936, New York, NY 10032, USA

<sup>2</sup> Department of Medicine, National University of Singapore, Singapore, Singapore

<sup>3</sup> Department of Gastroenterology and Hepatology, University Medical Cluster, National University Hospital, Level 10 NUHS Tower Block, Singapore 119228, Singapore

### Introduction

Caregiver burden is a phenomenon where caregivers or spouses of patients suffer as a result of the patient's primary illness. First described by Zarit et al. [1], in caregivers of patients with Alzheimer's dementia, caregiver burden has now been documented in several illnesses

including terminal cancer, fibromyalgia, rheumatoid arthritis, and osteoarthritis [2–4]. The burden experienced by caregivers encompasses physical, emotional, and economic hardships.

Until recently, the concept of caregiver burden had not been investigated in gastrointestinal disease. In 2013, Wong et al. [5] published the findings from a survey-based study aiming to determine the degree of burden to partners of patients with irritable bowel syndrome (IBS). In this study, the investigators found that overall burden was significantly higher among partners of patients with IBS than controls.

Unlike IBS which is a functional GI disorder with no structural disease elements, celiac disease (CD) is an organic disease characterized by small bowel mucosal inflammation, villous atrophy, and crypt hyperplasia which is triggered in genetically predisposed individuals by exposure to dietary gluten. CD can present with intestinal symptoms (diarrhea, steatorrhea, flatulence, etc.) or extraintestinal symptoms (dermatitis herpetiformis, anemia, reduced bone density, infertility, neuropsychiatric illness, autoimmune diseases, etc.), or it can be detected in asymptomatic individuals as part of the screening of high-risk populations. CD is associated with a significant increase in morbidity and mortality, and its treatment requires a strict, lifelong adherence to a gluten-free diet (GFD) [6–9]. Given the varied symptoms, comorbidities, and strict dietary modifications required for treatment, it is not surprising that many patients with CD regard it as a substantial burden on their quality of life. While there are multiple studies looking at the socioeconomic, psychological, and sexual satisfaction-related burden of CD on patients themselves, there have been no studies to date investigating the impact CD has on the partners of patients [10–19].

The aim of this study was to quantify the degree of burden to partners of patients with CD, identify factors that affect the perceived burden (including characteristics of the patient's CD symptomatology), and identify specific aspects of a relationship that are affected, including sexual intimacy.

## Methods

### Study Population

This was a cross-sectional study conducted at the Celiac Disease Center at Columbia University (Department of Medicine at Columbia University Medical Center; New York, NY) between September 2014 and September 2015. Five hundred and forty adult patients ( $\geq 18$  years of age) with biopsy-verified CD were invited to participate in the study. All patients had previously been seen at the Celiac

Disease Center, and they had provided consent to be contacted for research purposes. The study invitation was either e-mailed to the patients or given to them in-person during an office visit. Interested patients were contacted directly to explain the study aims and procedures. Only those patients reporting a current “partner” (defined as a live-in significant other who spends a significant amount of time with the patient) were eligible. If the patient was agreeable, their partner was then contacted to explain the study and establish his/her interest in participating.

### Ethics Approval

This study was approved by the Columbia University Institutional Review Board (#IRB-AAAO2300). Subjects were required to give verbal consent and allow their partners to be contacted by study personnel. Partners who agreed to participate also provided informed, verbal consent. Patients and partners were instructed to not share their answers with each other. The responses of patients and partners were collected and stored in a secure password-protected database. All answers were kept anonymous, and respondents were only identified by a study code.

### Survey Methodology

Study patients were required to complete an online survey using the *SurveyMonkey*<sup>®</sup> program (Survey Monkey, Inc., USA) that collected data on their: (1) demographics, (2) details regarding their CD, and (3) CD-related symptom severity. Similarly, partners completed a separate survey collecting data on their: (1) demographics, (2) relationship satisfaction, (3) burden, and (4) sexual relationship.

Collected demographic data included patient/partner age, sex, race, education (highest level completed), type of relationship, and number of years with the current partner. CD-related questions included disease duration, time of diagnosis related to the start of the current intimate relationship (before/after), and adherence to a GFD.

Patient CD symptom severity was measured using the Celiac Symptom Index (CSI). This is a validated 16-question survey that measures disease-specific symptom burden as perceived by the patient. With each individual question being scored on a scale from 1 to 5, the total score on the CSI is 80. Higher scores represent decreased quality of life [20].

Partner relationship satisfaction was measured using the Relationship Scale (RS). This is a validated 7-question instrument that quantifies the strength of a relationship as perceived by the respondents [21]. With each individual question being scored on a scale from 1 to 5, the total score on the RS is 35. Higher scores represent increased satisfaction with a relationship.

Partner burden was measured using the validated Zarit Burden Interview (ZBI). This is a 22-question instrument that examines and quantifies caregiver burden and distress associated with functional/behavioral impairments and the home care situation. With each individual question being scored on a scale from 0 to 4, the total score on the ZBI is 88. Higher scores represent increased caregiver burden. Previous studies have shown mean ZBI scores of 32.9, 22.1, 18.5, and 11.5 among caregivers of dementia patients, IBS patients, cancer patients, and controls, respectively [4, 5, 22, 23].

Partner sexual satisfaction was measured using a survey containing specific questions focused on areas that are most likely to be affected by CD. These questions focused on satisfaction with frequency of sexual activity (score: not at all, slightly, moderately, quite a bit, a great deal), sexual satisfaction (score: 5-point Likert scale), perception on how often CD and its symptoms interfere with the sexual relationship (score: not at all, slightly, moderately, quite a bit, a great deal), and perception on whether the patient uses CD symptoms to avoid sex (score: not at all, slightly, moderately, quite a bit, a great deal). Higher scores represent increased sexual satisfaction.

## Data Analysis

Descriptive statistics were calculated for patient/partner dyads for all demographics. Means and standard deviations were calculated for continuous variables, and frequencies were determined for categorical variables. Group characteristics were compared using paired *t* tests and analysis of variance, as appropriate.

Univariable analysis and multivariable logistic regression were used to assess the association between demographics, CD characteristics, and partner burden. Pearson's correlation coefficients were calculated and tested for significance for the relationship between partner ZBI and CSI, overall partner RS scores, and the score on the sexual relationship survey. Paired *t* tests and analysis of variance were used as appropriate.

All analyses were performed using SAS version 9.3 (SAS Institute Inc., Cary, NC).

## Results

Of the 540 patients who were invited to enroll in the study, 117 (22 %) consented to study participation. Ultimately, a total of 94 patient/partner pairs (80 %) fully completed the surveys and were studied. The mean age of the CD patients was 52.4 years (range 21–82 years), and a majority were female (71 %), white (98 %), and college-educated

(93 %). The mean age at CD diagnosis was 41.2 years, with 65 % reporting having CD for >5 years (mean duration of CD was 9.6 years). Nearly all patients (98 %) reported adherence to a strict GFD. Partners were of similar demographics, and patients and partners had been in relationships for a mean duration of 24.9 years, with 85 % being married. In total, 98 % of relationships were heterosexual. A full description of patient and partner demographics is listed in Table 1.

## Celiac Symptom Severity

Patients with CD reported a mean total CSI score of  $34.0 \pm 10.7$  (range 16–71, of a total 80 points). Based on the survey score interpretation guidelines proposed by the creators of the CSI [20], 45 % of CD patients ( $n = 42$ ) reported a score correlating with both high quality of life and excellent GFD adherence (CSI score  $\leq 30$ ). In contrast, 16 % ( $n = 15$ ) reported a CSI score associated with relatively poor quality of life and worse GFD adherence (CSI score  $\geq 45$ ). The most common ongoing symptoms reported by the patients were low energy (31 % reporting this “most” or “all of the time”) and bloating (18 % reporting this “most” or “all of the time”). Overall, 24 % of patients reported their overall health as fair or poor (rather than excellent or good).

**Table 1** Patient and partner demographics

	Patients ( $n = 94$ )	Partners ( $n = 94$ )
Sex—no. (%)		
Male	27 (29)	65 (69)
Female	67 (71)	29 (31)
Age, years—no. (%)		
20–39	19 (21)	18 (21)
40–59	38 (42)	34 (40)
>60	34 (37)	32 (38)
Race—no. (%)		
White	91 (98)	91 (97)
Other	2 (2)	3 (3)
Education level—no. (%)		
High school	7 (7)	8 (9)
College	37 (39)	42 (45)
Graduate	50 (53)	43 (46)
Duration of celiac disease, years—no. (%)		
<5	33 (35)	—
5–10	31 (33)	—
>10	29 (31)	—
Self-reported adherence to strict gluten-free diet—no. (%)		
Yes	91 (98)	—
No	2 (2)	—

## Degree of Partner Burden

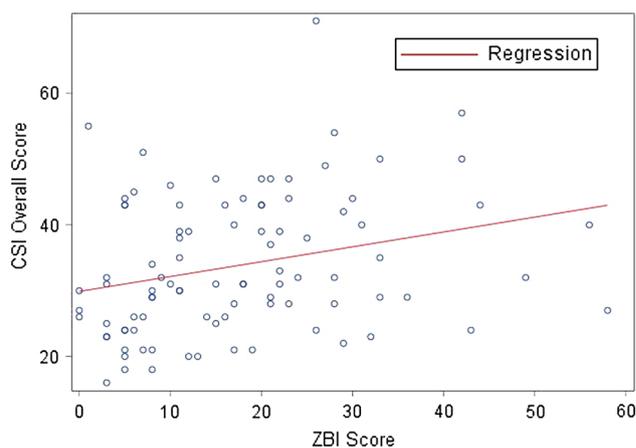
Partners of patients with CD reported a mean total ZBI score of  $17.5 \pm 12.8$  (range 0–58, of a total 88 points). Based on the score interpretation guidelines proposed by Hebert et al. [24], 63 % of partners ( $n = 59$ ) reported little or no burden (ZBI score 0–21), 29 % ( $n = 27$ ) reported mild-to-moderate burden (ZBI score 21–40), and 8 % ( $n = 7$ ) reported moderate-to-severe burden (ZBI score 41–60). No partners reported severe burden (ZBI score 61–88).

Common concerns experienced at least “sometimes” by partners included: feeling that the patient is dependent (reported by 66 % of partners), feeling they should be doing more for the patient (50 %), being afraid of what the future holds for the patient (46 %), and feeling they could be doing a better job for the patient (44 %). In contrast, a majority of partners reported that the patient’s CD “rarely” or “never” resulted in financial hardships (82 % of partners), a suffering social life (82 %), or strained relationships with family (74 %).

When looking at the association between specific aspects of burden and relationship duration, a significantly higher proportion of partners in relationships for  $\geq 10$  years reported “quite frequently” or “nearly always” being afraid of what the future holds for the patient compared to partners in relationships for  $< 10$  years (24 vs. 4 %,  $p = 0.03$ ). Though not statistically significant, a higher percentage of patients in relationships for  $\geq 10$  years also reported “quite frequently” or “nearly always” feeling uncertain about the continued care of the patient (6 vs. 0 % of partners in shorter relationships). In contrast, a significantly higher proportion of patients in relationships of  $< 10$  years duration reported frequently experiencing financial strain due to the patient’s CD (22 vs. 1 %,  $p < 0.05$ ), and there was also a trend toward partners in shorter relationships feeling that caring for the patient affected their ability to meet other family or work responsibilities (17 vs. 7 % of partners in longer relationships).

## Correlation Between Partner Burden and CD Symptom Severity

When considered as continuous variables, the ZBI score of the partner was directly correlated with the CSI score of the patient (Pearson  $r = 0.27$ ;  $p = 0.008$ ). This is shown in Fig. 1. When CSI score was categorized as low (score  $\leq 30$ ), moderate (31–44), and high ( $\geq 45$ ), there was a nonsignificant trend showing that higher CSI scores were associated with the presence of at least mild-to-moderate partner burden with a ZBI score  $> 21$ : 57 % of partners of patients with a CSI score  $\geq 45$  reported at least mild-to-



**Fig. 1** Linear regression plot of Patient Celiac Symptom Index score by Partner Zarit Burden Interview score. Legend:  $r = 0.27$ ;  $p = 0.008$

moderate burden versus 26 % of partners of patients with a CSI score  $\leq 30$  ( $p = 0.09$ ).

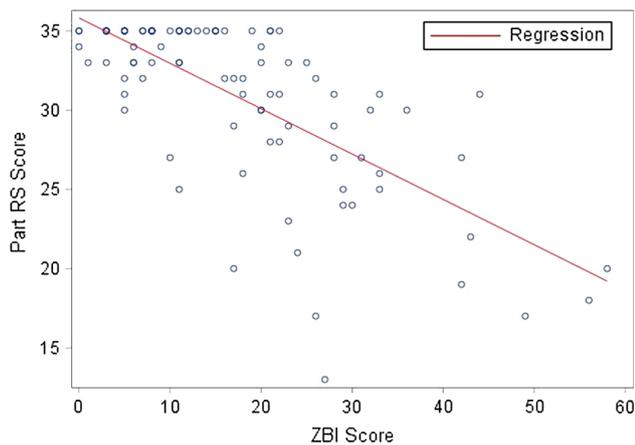
## Relationship Satisfaction, Sexual Satisfaction, and Partner Burden

Partners reported a mean total RS score of  $30.8 \pm 5.3$  (range 13–35, of a total 35 points) and a mean total sexual satisfaction score of  $20.2 \pm 4.1$  (range 5–25, of a total 25 points). In total, 23 % of partners ( $n = 22$ ) reported moderate-to-low overall satisfaction with their relationship (RS score  $< 28$ ), and 14 % ( $n = 12$ ) reported moderate-to-low sexual satisfaction ( $< 15$  total points on the sexual satisfaction questions). While only 8 % of partners felt that the patient’s CD and its symptoms interfered with their sexual relationship and 2 % felt that the patient used their CD to avoid sex, 33 % of partners reported “slight” or “no” satisfaction with their frequency of sexual intercourse and 22 % reported “slight” or “no” satisfaction with their quality of sexual intercourse.

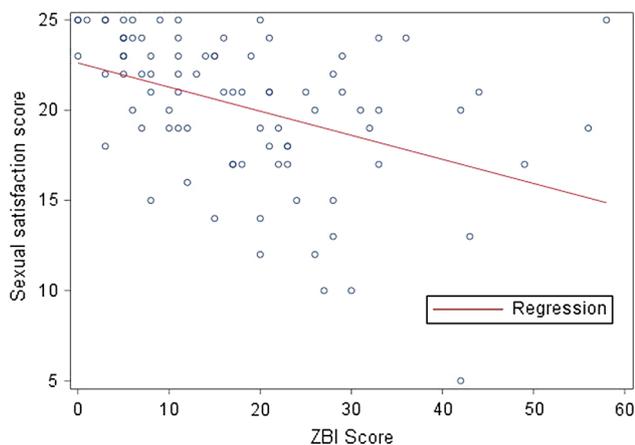
There were moderate-to-strong inverse relationships between partners’ burden and relationship quality (Pearson  $r = -0.70$ ;  $p < 0.001$ ) and sexual satisfaction (Pearson  $r = -0.42$ ;  $p < 0.001$ ). This is shown in Figs. 2 and 3. This suggests that higher burden in partners of patients with CD is associated with a weaker partner relationship and a lower sexual satisfaction.

## Predictors of Partner Burden: Univariate and Multivariate Analysis

Neither patient/partner demographics (including sex, age, and level of education), relationship characteristics (duration, type, and current sexual activity), nor CD diagnostic characteristics (duration of CD and diagnosis before/after



**Fig. 2** Linear regression plot of Partner Relationship Scale score by Partner Zarit Burden Interview score. Legend:  $r = -0.70$ ;  $p < 0.001$



**Fig. 3** Linear regression plot of partner sexual satisfaction score by Partner Zarit Burden Interview score. Legend:  $r = -0.42$ ;  $p < 0.001$

the start of the current relationship) were associated with partner burden as measured by the ZBI score ( $>21$ ). While there was a trend toward increasing patient CSI being associated with partner burden, the only two factors predictive of at least mild-to-moderate partner burden were partner relationship satisfaction (81 % for RS score  $< 28$  vs. 24 % for RS score  $\geq 28$ ,  $p < 0.01$ ) and partner sexual satisfaction (67 % for sexual satisfaction score  $< 15$  vs. 33 % for sexual satisfaction score  $\geq 15$ ,  $p = 0.03$ ). The full results of the univariate analysis assessing predictors of partner burden are presented in Table 2.

On multivariate analysis controlling for several patient/partner demographic factors, CD diagnostic features, relationship characteristics, patient CD symptom index, and partner sexual satisfaction, partner relationship satisfaction remained a significant predictor of at least mild-to-moderate partner burden. Compared to partners reporting high satisfaction in their current relationship (RS

score  $\geq 28$ ), those having moderate-to-low overall satisfaction with their relationship were more likely to experience at least mild-to-moderate burden (OR 17.06, 95 % CI 2.88–101.09,  $p = 0.002$ ). In the multivariable model, the only other predictor of at least mild-to-moderate partner burden was relationship duration  $\geq 10$  years (OR 14.42, 95 % CI 1.69–123.84,  $p = 0.02$ ). The full results of the multivariate analysis assessing predictors of partner burden are presented in Table 3.

## Discussion

An extensive body of the literature has established that CD can be quite burdensome for patients and commonly results in reduced health-related quality of life [8–19]. Patient burden is driven not only by the symptoms of CD [20], but also by the social and financial restrictions that result from adherence to a GFD [8]. Given the multifaceted manner in which CD can affect patients in their day-to-day life, it is not unreasonable to expect that the impact of CD may extend to their relationship partners. Ours is the first study investigating the concept of partner burden in CD. Our study shows that partner burden is common in CD, with more than one-third of partners experiencing at least mild-to-moderate burden. Further, partner burden increases with poorer sexual and relationship satisfaction, and it is directly correlated with the patient's CD symptom index.

Until recently, the concept of caregiver burden had only been investigated in chronic oncologic, neurologic, and rheumatologic diseases [1–4]. These studies demonstrated that a patient's illness can result in not only physical and economic strain for their caregiver, but also significant emotional burden. In 2013, Wong et al. [5] were the first to report caregiver burden in gastrointestinal disease. In this study, 152 patients with IBS and their partners completed questionnaires including the Functional Bowel Disease Severity Index, the ZBI, RS, and questions on sexual relationships. Thirty-nine healthy controls and their partners were also surveyed. This study showed that burden was significantly higher among partners of IBS patients (mean ZBI score 22.1) than controls (mean ZBI score 11.5), and the degree of burden was directly related to IBS severity and inversely correlated with partners' rating of relationship quality ( $R = -0.60$ ) and sexual satisfaction ( $R = -0.56$ ).

The results of our study are consistent with the findings that were reported by Wong et al. The overall partner burden observed in our patients with CD (ZBI score 17.5) was notably higher than in the controls reported by Wong et al., and it was in line with the partner burden seen with IBS. Further, as in IBS, a direct correlation was found between patients' gastrointestinal symptom index and the

**Table 2** Univariate analysis: predictors of partner burden

	No partner burden (ZBI score 0–21)	Mild-to-moderate partner burden (ZBI score > 21)	<i>p</i> value
Patient sex—no. (%)			0.59
Male	16 (59)	11 (41)	
Female	43 (65)	23 (35)	
Partner sex—no. (%)			0.85
Male	41 (64)	23 (36)	
Female	18 (62)	11 (38)	
Patient age, years—no. (%)			0.34
20–59	34 (61)	22 (39)	
>60	24 (71)	10 (29)	
Partner age, years—no. (%)			0.84
20–39	33 (65)	18 (35)	
>60	20 (63)	12 (38)	
Patient education level—no. (%)			0.35
High school	3 (43)	4 (57)	
College	26 (70)	11 (30)	
Graduate	30 (61)	19 (39)	
Partner education level—no. (%)			0.23
High school	3 (37)	5 (63)	
College	26 (62)	16 (38)	
Graduate	29 (69)	13 (31)	
Patient duration of celiac disease—no. (%)			0.69
<5	19 (58)	14 (42)	
5–10	20 (65)	11 (35)	
>10	19 (68)	9 (32)	
Duration of relationship, years—no. (%)			0.23
<10	17 (74)	6 (26)	
≥10	42 (60)	28 (40)	
Type of relationship—no. (%)			0.88
Spouse	51 (64)	29 (36)	
Fiance/other	8 (62)	5 (38)	
Celiac diagnosis before/after relationship—no. (%)			0.69
Before	10 (59)	7 (41)	
After	48 (64)	27 (36)	
Current sexual activity—no. (%)			0.07
Yes	49 (65)	26 (35)	
No	4 (36)	7 (64)	
Patient CSI score—no. (%)			0.09
0–30	31 (74)	11 (26)	
31–44	22 (59)	15 (41)	
>45	6 (43)	8 (57)	
Partner RS score—no (%)			<0.01
<28	4 (19)	17 (81)	
≥28	55 (76)	17 (24)	
Partner sexual satisfaction score—no. (%)			0.03
<15	4 (33)	8 (67)	
≥15	50 (67)	25 (33)	

**Table 3** Multivariate analysis: predictors of partner burden (ZBI score > 21)

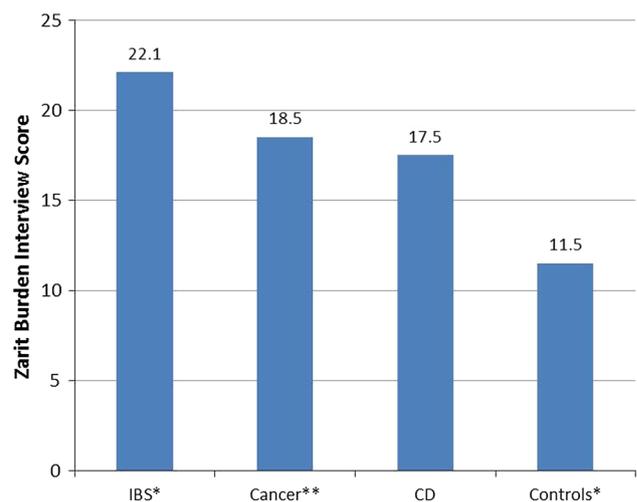
	Odds ratio	95 % CI	<i>p</i> value
Patient education level—no. (%)			
High school	1		
College	0.44	0.03–6.24	0.55
Graduate	0.86	0.06–12.63	0.91
Partner education level—no. (%)			
High school	1		
College	0.69	0.09–5.37	0.72
Graduate	0.29	0.04–2.41	0.25
Patient duration of celiac disease—no. (%)			
<5	1		
5–10	0.37	0.08–1.74	0.21
>10	0.36	0.07–1.92	0.23
Duration of relationship, years—no. (%)			
<10	1		
≥10	14.42	1.69–123.84	0.02
Celiac diagnosis before/after relationship—no. (%)			
Before	1		
After	0.16	0.02–1.14	0.07
Current sexual activity—no. (%)			
No	1		
Yes	1.23	0.16–9.29	0.84
Patient symptom severity (CSI score)—no. (%)			
Low (0–30)	1		
Moderate (31–44)	1.26	0.28–5.63	0.76
High (>45)	1.03	0.11–9.34	0.98
Partner relationship score (RS)—no. (%)			
High (≥28)	1		
Low (<28)	17.06	2.88–101.09	0.002
Partner sexual satisfaction score—no. (%)			
High (>15)	1		
Low (0–15)	2.23	0.28–17.78	0.45

degree of burden experienced by their partners. Although CD and IBS are distinct entities in that CD is an organic disease, while IBS is a functional disorder, the two disease processes share several symptoms (diarrhea, abdominal pain, bloating, etc.), and the treatment of patients with IBS often requires dietary modifications [25]. This overlap in patient symptoms and management may explain why both diseases result in similar partner burden. One important distinction that should be noted between IBS and CD, however, is that emotional stress seems to play a more significant role in symptom exacerbation among IBS patients [26]. Since neither our study nor that performed in IBS measured cause and effect between patient symptoms and partner burden, it is possible that partners' burden and relationship stressors resulted in worsening of patients' symptoms. Although psychological factors do play a role in

the health of patients with CD [27], this seems more plausible in a functional disorder such as IBS.

Interestingly, the degree of burden experienced by partners of patients with CD is also remarkably similar to the reported burden with other chronic, organic diseases such as terminal cancer (ZBI score 18.5) [23]. Figure 4 shows this comparison. It is important to note that the ZBI is not specifically designed to allow for comparison across disease processes, and the responsibilities and hardships borne by partners of those with cancer are certainly different than those experienced by CD partners. However, the similar partner burden scores between CD and cancer does demonstrate that like other chronic illnesses, CD requires a level of understanding, acceptance, and support from the loved ones of those with the disease.

In attempting to identify factors that affect partner burden, we found that both overall relationship satisfaction and sexual satisfaction were significant predictors. As in IBS, a significant correlation was seen between a weak relationship (as reported by the partner) and high partner burden. Whether this link is causative or associative is unclear, but the strength of the correlation ( $R = -0.70$ ) and its consistency across two distinct gastrointestinal diseases does suggest that the quality of the patient/partner relationship is an important area for physicians to address when identifying the various social stresses that result from CD. With regard to sexual satisfaction, while only a minority of partners felt that the patient's CD and its symptoms interfered with their sexual relationship, we again found a significant correlation between lower sexual satisfaction and higher partner burden. A previous study by Ciacci et al. [19] evaluating 55 adults with CD and 51 age-



**Fig. 4** Partner burden for different types of patients (as measured by mean total Zarit Burden Interview score scores). Legend: \*IBS and control data from Wong et al. [5]. \*\*Cancer data from Higginson et al. [23]

and sex-matched healthy controls demonstrated that patients with CD had a significantly lower frequency of sexual intercourse and a lower prevalence of satisfaction with their sexual life. Our study is the first to shed light on this issue from the perspective of the partners of patients with CD. It is important to note that reduced sexual satisfaction was overall rare among the partners of our patients, and partner sexual satisfaction was not a predictor of burden in the multivariate analysis. While these findings suggest that reduced sexual satisfaction was not significantly associated with partner burden in our study, we feel that this is an understudied area that warrants further investigation with detailed and validated sexual function and satisfaction measurements in a robust and diverse sample of CD patients. Even in the rare instances where reduced sexual satisfaction may contribute to perceived burden by a spouse or partner, it can certainly lead to strain in the relationship, and this is a potentially important topic that should be addressed in the counseling of patients with CD.

One surprising predictor of partner burden in CD was the duration of the patient and partners' relationship. In our multivariable model, we found that compared to those in relationships of <10-year duration, partners who had been in relationships for at least 10 years were significantly more likely to experience at least mild-to-moderate burden. At first glance, this association appears counterintuitive. With long-standing relationships, it might be expected that not only will patients be more educated and capable of managing their CD and adhering to a GFD, but partners will also be able to better cope with the patients' symptoms and the social impact of CD. This should be especially true in our study patients, who had CD with a mean duration of nearly 10 years. The explanation for why long-term partners experienced higher burden may be found in the specific aspects of burden that the partners reported. While objective stressors such as the financial hardships resulting from CD were more commonly reported by partners in short-duration relationships (<10 years), it was much more common for partners in longer-term relationships to express feelings of fear and uncertainty regarding what the future holds for their loved ones. These are emotions that may undoubtedly develop as patients and partners progress in their relationships, as the burden of CD shifts from the short-term focus on diagnosis and dietary modifications to the prognostic implications and uncertainties of a chronic illness. Our findings suggest that these types of emotional stress may play an important role in the burden experienced by partners of patients with CD—especially over time. Yet again, this emphasizes the meaningful burden experienced by CD partners, and it stresses the importance including the partner in the education, counseling, and decision-making process when caring for a patient with CD.

We acknowledge several limitations with our study. First, our study design did not incorporate a control population of healthy subjects and their partners. Although direct comparison with a control would have allowed us to confirm that our measurement of burden was not confounded by other factors in the patient/partner relationship, we do point out that the overall burden experienced by the partners of our CD patients was higher than that reported in the control population in the recent study of partner burden in IBS [5]. Since these two studies utilized the same surveys for measurement of partner burden, relationship satisfaction, and sexual satisfaction, we hope the comparison of our results offers some insight into the true partner burden in CD. Second, although we invited more than 500 patients with biopsy-proven CD to participate in our study, the size of our final study population was limited by a low response rate (22 %), and our study population was heavily comprised of older, female, well-educated, white patients and partners who had been in very long-standing relationships (nearly 25 years on average). Nonetheless, our study patients were fairly representative of the overall population seen at our tertiary care referral center, and their demographics were very similar to those reported in a recent study that also evaluated patients from the Celiac Disease Center at Columbia University [28]. The small size and overall homogeneity of our study population reduced our statistical power, resulted in wide confidence intervals for certain study outcomes, and likely limited the generalizability of our results. One particular population that should be the focus of future studies is patients and partners who have been in relationships of shorter duration. The impact of CD, its symptoms, and the adherence to a GFD may be different in these earliest years of a committed relationship. Third, despite all patients and partners being instructed to complete surveys independently, the nature of the online survey precluded us from verifying that patients and partners did not discuss questions prior to answering. We expect, however, that the measures that were in place to ensure anonymity likely resulted in honest survey responses.

In conclusion, this study shows that CD commonly results in partner burden. The degree of partner burden is directly correlated with the patient's symptoms, and it increases with both reduced sexual and relationship satisfaction. Healthcare providers should make an effort to address these important relationship factors in their care of patients with CD.

**Author contributions** The guarantor of this manuscript is Peter HR Green. Specific author contributions include: Abhik Roy contributed to study concept and design, acquisition of data, analysis and interpretation of data, drafting of the manuscript, and critical revision of the manuscript for important intellectual content; Maria Minaya, Milka Monegro, Jude Fleming, Reuben K Wong, Suzanne Lewis,

Benjamin Lebwohl, Peter HR Green contributed to study concept and design, acquisition of data, and critical revision of the manuscript for important intellectual content. All authors approved the final version of the manuscript.

### Compliance with ethical standards

**Conflict of interest** Abhik Roy, Maria Minaya, Milka Monegro, Jude Fleming, Reuben K Wong, Suzanne Lewis, Benjamin Lebwohl, and Peter HR Green declare that they have no conflict of interest (financial, professional, or personal) that is relevant to the manuscript.

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