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Concordance and Discordance Between Patient-reported Remission, Patient-reported Outcomes, and Physician Global Assessment

Kendra J. Kamp, PhD,^{*}  Stephen E. Hawes, PhD,^{*} Chung Sang Tse, MD,[†]
Siddharth Singh, MD,[†]  Nhu Dang, BA,[‡] Ridhima Oberai, BS,[§] S. Alandra Weaver, MPH,[§]
Gil Y. Melmed, MD, MS,[¶] Corey A. Siegel, MD, MS,^{||} and Welmoed K. van Deen, PhD, MD,^{**} on
behalf of IBD Qorus

^{*}University of Washington, Seattle, WA, United States

[†]University of California - San Diego, San Diego, CA, United States

[‡]Brown University, Providence, RI, United States

[§]Crohn's and Colitis Foundation, New York, NY, United States

[¶]Cedars-Sinai Medical Center, Los Angeles, CA, United States

^{||}Dartmouth-Hitchcock Medical Center, Hanover, NH, United States

^{**}Erasmus School of Health Policy and Management, Rotterdam, the Netherlands

Address correspondence to: Welmoed K. van Deen, Erasmus School of Health Policy and Management, Health Technology Assessment, Erasmus University Rotterdam, Burgemeester Oudlaan 50, Bayle (J) Building Room J8-55, 3062PA Rotterdam, the Netherlands (vandeen@eshpm.eur.nl).

Background: Although validated patient-reported outcome (PRO) measurements can categorize patients with inflammatory bowel disease (IBD) into clinical remission or active disease, patients may have different definitions of remission. The purpose of this study was to compare patient-defined remission to remission based on PRO measures and physician global assessment (PGA) and to understand the clinical and demographic factors associated with disagreements.

Methods: We retrospectively analyzed 3257 de-identified surveys from 2004 IBD patients who consented to participate in the Crohn's and Colitis Foundation's IBD Qorus Learning Health System between September 2019 and February 2021. We used logistic regression models with generalized estimating equations to analyze the clinical and demographic factors (eg, age, disease duration, health confidence) associated with discordance between patient-defined remission (yes/no) and PRO-defined remission for ulcerative colitis (UC; PRO2: stool frequency, rectal bleeding) and Crohn's disease (CD; PRO-3: average number of liquid stools, abdominal pain, well-being).

Results: Among patients with UC, overall concordance was 79% between patient self-report and PRO2-defined remission and 49% between patient self-report and PGA-defined remission. Among patients with CD, overall concordance was 69% between patient self-report and PRO3-defined remission and 54% between patient self-report and PGA-defined remission. Patients in PRO-defined remission were more likely to report active disease if they had IBD <5 years and low health confidence. Patients with PRO-defined active disease were more likely to report remission if they were not using prednisone and had high health confidence.

Conclusion: Discordance exists between how remission is defined by patients, PRO measures, and PGA.

Lay Summary

Discordance between patients' self-reported remission and remission defined based on patient-reported outcomes was observed in 31% of Crohn's disease visits and 21% of ulcerative colitis visits. Disease duration and health confidence were associated with discordance.

Key Words: inflammatory bowel disease, patient-reported outcomes, remission

Introduction

Inflammatory bowel diseases (IBD) are characterized by inflammation of the gastrointestinal tract and include ulcerative colitis (UC) and Crohn's disease (CD).^{1,2} Patients can experience a variety of symptoms including abdominal pain, diarrhea, and bloody stool. The goal of treatment is to reduce the underlying inflammation and associated symptoms. Yet, despite the resolution of symptoms, inflammation might persist. Conversely, symptoms may continue in the absence of underlying inflammation.²⁻⁴ As such, a variety of measurement

approaches have been used to monitor and classify disease activity. Some of these measures focus on clinician-reported disease activity, which often includes objective markers of inflammation (eg, C-reactive protein [CRP], calprotectin, endoscopy),⁵ whereas others represent patient-reported outcomes (PROs), which focus on symptoms.^{6,7}

Patients have various definitions of remission. For example, some define remission as being steroid-free and having no symptoms, which is similar to clinical definitions.^{8,9} However, others define remission as a decrease in abdominal pain and

Key Messages

What is already known?

- Various definitions exist for “remission” of inflammatory bowel disease.

What is new here?

- Discordance exists between how remission is defined by patients, patient-reported outcomes, and physician global assessments.
- A yes/no measure of patient-defined remission has high concordance with patient-reported outcome measures of symptomatic disease activity but low concordance with physician global assessment.
- Disease duration, health confidence, prednisone use, opioid use, and recent emergency department visits are associated with discordance.

How can this study help patient care?

- Asking about patient-defined remission can promote a patient-centered approach to inflammatory bowel disease management.

bowel movements, even without a complete resolution of symptoms,^{10,11} which is in contrast to accepted definitions of clinical remission that require patients to have no or few symptoms in the past 6 months.^{11,12} Instead, patients often accept a new normal of increased symptoms, which may lead to a delay in seeking effective treatments.¹¹ Overall, patients primarily define remission as a resolution of symptoms, whereas providers define remission primarily based on test results.¹³

Examining patient-reported remission may be a valuable approach to better understand remission from the perspective of patients and can assist in aligning shared decision-making between patients and health care providers. The purpose of this study was to compare patient-defined remission to remission based on PRO measures and physician global assessment (PGA) and to understand the clinical and demographic factors associated with disagreement.

Materials and Methods

Ethical Considerations

Institutional review board (IRB) approval for this study was exempted by Dartmouth College, the central IRB overseeing the IBD Qorus Learning Health System, due to the de-identified nature of the data set. All patients consented to participate in IBD Qorus and to the use of their de-identified data for research purposes.

Study Design and Setting

Retrospective data were obtained from the Crohn's and Colitis Foundation's IBD Qorus Learning Health System collected between September 2019 and February 2021. The IBD Qorus is a learning health system composed of academic and private gastroenterology practices.¹⁴ Adults with IBD who consented to participate in IBD Qorus received an email before their gastroenterology clinic appointments with a link to an electronic survey that queried their health status. The electronic survey asked specific questions related to the patient's

primary concerns or goals, symptoms, well-being, recent health care utilization, and medication use.

Study Participants

Participants who completed at least 1 survey between September 2019 and February 2021 were eligible for this current analysis. Surveys were excluded if there were missing data on self-reported remission and PROs ($n = 2076$). Patients could have completed multiple surveys during the time frame, which is accounted for in the data analysis section. Patients with an ostomy and IBD-unclassified were excluded due to an inability to quantify bowel movements and a lack of standardized PRO measures.

Measures

Patient-defined remission

To assess patient-defined remission, patients were asked the following question: “Do you feel your disease is currently in remission (by remission we mean a complete absence of IBD-related symptoms)?” Response options were yes or no.

Patient-reported outcomes

The PRO2 was used for UC and asked patients about rectal bleeding and stool frequency.⁶ Remission was defined as no blood in the stool and a normal (or fewer than normal) number of stools.⁶ The PRO3 was used for CD and included 3 questions these points : number of loose stools, abdominal pain, and general well-being.⁷ Patients were categorized as in remission if they reported 2 or fewer loose stools, no or mild abdominal pain, and feeling generally well or slightly under par.⁷

Physician global assessment

Health care providers completed the physician global assessment (PGA), in which they selected if the patient had normal, mild, moderate, or severe disease activity.¹⁵ Physician global assessment values were not available for all visits. Values were included if providers completed them within 14 days of the patient's survey.

Health care utilization

Health care utilization was assessed with self-report of hospitalization or emergency department (ED) visit due to IBD in the past 6 months, which has high sensitivity and specificity.¹⁶

Health confidence

Patient confidence in disease management was assessed using the validated Wasson Health Confidence Scale, by asking the question, “How confident are you that you can control and manage most of your health problems related to IBD?” Patients responded on a 0 to 10 scale, with 0 indicating not confident at all and 10 indicating very confident.¹⁷ High health confidence was defined as a score of 7 or above.^{18,19} High health confidence has been associated with improved health outcomes including a reduced risk for IBD flares.^{20,21}

Demographic and clinical characteristics

Other characteristics included gender (male/female/other), age (continuous variable in years), type of IBD (UC or CD),

duration of disease, disease extent (UC, proctitis, left-sided, pancolitis, J-pouch; CD, ileal, colonic, ileocolonic, J-pouch), past surgeries, current use of prednisone (yes/no), and current opioid use (yes/no).

Data Analysis

Data analysis was performed using R version 4.2.1 (RStudio, Boston, MA). For patients who completed multiple surveys within the study period, we used the first completed survey for demographic and disease characteristics. For the remaining analyses, all follow-up surveys were included. Concordance and discordance were examined between patient-defined remission and PRO-defined remission, steroid-free PRO remission, and PGA. The PRO2 (UC) and PRO3 (CD) were dichotomized based on existing literature as described previously.^{6,7} Steroid-free remission was defined as meeting the criteria for PRO remission along with no prednisone use in the past 6 months. The PGA was dichotomized into remission (which includes normal) or active disease (which includes mild, moderate, or severe active disease). All analyses were stratified by IBD subtype (UC vs CD). Descriptive concordance/discordance analyses were performed at the visit-level and were not adjusted for correlations due to multiple observations for ease of interpretation. Multivariable logistic regression models were built using generalized estimating equations (GEEs) with an exchangeable correlation using the R package, *geepack*,²² to account for correlated data (ie, patients with multiple surveys over time). Multivariable analysis was conducted separately for each disease type (UC and CD) with the following clinical and demographic predictors in the model: gender, duration of IBD, current prednisone use, current opioid use, recent hospitalization, recent emergency room visit, and patients' health confidence. Predictors were selected based on previous factors associated with patient-provider discordance^{23,24} and factors associated with higher levels of symptoms based on the literature review.^{25,26} Symptom measures were not included as predictors because they comprised the outcome variable. Significance was set at $P < .05$.

Results

Demographics and Clinical Characteristics

We retrospectively analyzed 3257 de-identified surveys from 2004 unique patients (806 UC; 1198 CD). Patients with UC were on average 44.1 years old (standard deviation [SD], 15.5), and 58% were female. Patients with CD were on average 44.0 years old (SD, 15.6), and 56% were female (Table 1).

Concordance and Discordance

Ulcerative colitis

In 668 (51%) of 1316 patient visits, patients self-reported to be in remission, whereas 55% were in remission based on the PRO2 (Table 2). Of the people in PRO2 defined remission, 77% also reported being in remission, although 23% reported active disease. Of the people with PRO2 defined active disease, 81% also reported having active disease, and 19% reported being in remission. Overall concordance was 79% between patient self-report and PRO2-defined remission. Discordance in patient-defined remission was primarily

Table 1. Demographic and clinical characteristics from the IBD Qorus Collaborative.^a

	UC Patients (n = 806)	CD Patients (n = 1198)
Age, M (SD)	44.1 (15.5)	44.0 (15.6)
Gender, n (%)		
Female and other	466 (57.8%)	672 (56.1%)
Male	340 (42.2%)	526 (43.9%)
Duration of IBD, n (%)		
<5 years	246 (30.5%)	300 (25.0%)
5-10 years	144 (17.9%)	207 (17.3%)
11-15 years	227 (28.2%)	434 (36.2%)
>15 years	189 (23.4%)	257 (21.5%)
Ulcerative Colitis Extent, n (%)		
Proctitis	100 (12.4%)	NA
Left-sided	204 (25.3%)	NA
Pan-colitis	424 (52.6%)	NA
J-pouch	31 (3.8%)	NA
Not sure	47 (5.8%)	NA
Crohn's Disease Phenotype, n (%)		
Non-Strictureing and Non-Penetrating	NA	588 (49.1%)
Strictureing and Non-Penetrating	NA	306 (25.5%)
Penetrating and Non-Strictureing	NA	142 (11.9%)
Penetrating and Strictureing	NA	157 (13.1%)
Crohn's Disease Location, n (%)		
Ileal	NA	321 (26.8%)
Colonic	NA	248 (20.7%)
Ileocolonic	NA	567 (47.3%)
J-pouch	NA	19 (1.6%)
Not sure	NA	5 (0.4%)
Upper GI involvement, n (%)	NA	36 (3.0%)
Perianal involvement, n (%)	NA	183 (15.3%)
No. patient visits, n (%)		
1 Visit	522 (39.7%)	763 (39.2%)
2 Visits	322 (24.4%)	502 (25.8%)
3 Visits	204 (15.5%)	330 (16.9%)
4 + Visits	268 (20.4%)	352 (18.1%)

^aDemographics and clinical characteristics are presented based on the patients first visit data. NA indicates not applicable. Abbreviations: SD, standard deviation; n, number, IBD, inflammatory bowel disease; GI, gastrointestinal; UC, ulcerative colitis; CD, Crohn's disease.

influenced by tolerance of an increased stool frequency, as 25% of patients with 1 to 2 stools more than normal reported being in remission (Table 3). A subset of 397 visits also had an associated PGA score obtained within 2 weeks. Of the people in PGA remission, 53% reported being in remission. Of those with PGA active disease, 60% reported active disease. Overall concordance between patient self-report and PGA-defined remission was 49%.

Table 2. Concordance and discordance of patient-defined remission with disease activity measures among patients with ulcerative colitis and Crohn's disease.^a

N (%)	Ulcerative Colitis		Crohn's Disease	
	Patient-defined Remission (n = 668)	Patient-defined Active Disease (n = 648)	Patient-defined Remission (n = 929)	Patient-defined Active Disease (n = 1018)
PRO				
Remission	553 (77)	165 (23)	781 (63)	453 (37)
Active Disease	115 (19)	483 (81)	148 (21)	565 (79)
Steroid-Free PRO				
Remission	532 (78)	147 (22)	763 (65)	411 (35)
Active Disease	136 (21)	501 (79)	166 (21)	607 (79)
	Patient-defined Remission (n = 218)	Patient-defined Active Disease (n = 179)	Patient-defined Remission (n = 277)	Patient-defined Active Disease (n = 298)
PGA				
Remission	144 (53)	130 (47)	178 (52)	167 (48)
Active Disease	74 (60)	49 (40)	99 (43)	131 (57)

^aData presented in this table is based on survey level data and is therefore unadjusted for multiple surveys from the same participant. Percentages are row percentages for each disease type (ulcerative colitis and Crohn's disease). Abbreviations: PRO, patient-reported outcomes, PGA, physician global assessment.

Crohn's disease

In 929 (48%) of 1947 patient visits, patients self-reported to be in remission, although 63% were in remission based on the PRO-3 (Table 2). Of those in PRO-3 defined remission, 63% reported being in remission, whereas 37% reported being in active disease. Of those with PRO-3 defined active disease, 79% reported being in active disease, and 21% reported being in remission. Overall concordance was 69% between patient self-report and PRO3-defined remission. Discordance was primarily influenced by patients with a tolerance of mild to moderate symptoms (Table 3). A subset of 575 visits also had an associated PGA score obtained within 2 weeks. Of the people who were in PGA remission, 52% also reported being in remission. Of those with PGA active disease, 57% also reported active disease. Overall concordance between patient self-report and PGA-defined remission was 54%.

Predictors of Discordance

Patients in PRO-defined remission

Among patients who were in remission based on their PROs, those who were diagnosed with IBD for <5 years (UC odds ratio [OR] 2.0, 95% CI, 1.2-3.3; CD, OR 1.5, 95% CI, 1.0-2.2) compared with those diagnosed for more than 15 years were more likely to report having active disease (Table 4). In contrast, patients with high health confidence (7+) were less likely to report having active disease (UC, OR 0.4; 95% CI 0.2-0.6; CD, OR 0.2; 95% CI, 0.2-0.4). Additionally, CD patients were more likely to report having active disease despite being in PRO-based remission if they were using prednisone (OR, 3.6; 95% CI, 1.8-7.2) or opioids (OR, 4.4; 95% CI, 1.6-12.1) or if they had an IBD-related emergency department visit in the past 6 months (OR, 3.2; 95% CI, 1.5-6.9).

Patients with PRO-based active disease

Among patients who were in active disease based on their PROs, those with high health confidence (UC, OR 4.8; 95%

CI, 2.9-7.9; CD, OR 4.3, 95% CI, 2.8-6.8) were more likely to report being in remission (Table 5). Conversely, those who were using prednisone (UC, OR 0.4, 95% CI, 0.2-0.8; CD, OR 0.4, 95% CI, 0.2-0.97) and CD patients who were using opioids (OR, 0.2; 95% CI, 0.1-0.9) were less likely to report being in remission. Additionally among patients with CD, those with a diagnosis for <5 years (OR, 0.3; 95% CI, 0.2-0.6) had a lower odds of discordance compared with those with a diagnosis for more than 15 years.

Discussion

This study examined the concordance and discordance between patient-defined remission compared with remission based on PRO and PGA measures. We found that a yes/no measure of patient-defined remission overall was highly concordant with PRO measures evaluating abdominal pain, diarrhea, and rectal bleeding. However, patient-reported remission had low concordance with PGA, highlighting differences in the way that patients and health care providers assess remission. Discordance was more prevalent in patients with CD, which is consistent with the fact that symptoms and objective markers of disease activity are poorly correlated in CD.²⁷ Additionally, we examined factors associated with discordant views between patient-defined remission and PROs, finding that disease duration, health confidence, prednisone use, opioid use, and an ED visit in the past 6 months were all associated with discordance. Factors associated with discordance differed based on disease type (UC vs CD).

Previous research has highlighted differences in definitions of remission between patients and providers.^{9,10,13} Likewise, we found discordance between patient-defined remission with PRO and PGA-defined remission. Remission defined by PGA may take into consideration objective measures such as endoscopic, histologic, or biochemical findings, which are known discrepancies with symptoms and could drive the low concordance levels observed with PGA.²⁻⁴ When examining

Table 3. Survey responses broken down based on patients' self-reported remissions status.

	Ulcerative Colitis		Crohn's Disease	
	Patient-defined Remission (n = 668)	Patient-defined Active Disease (n = 648)	Patient-defined Remission (n = 929)	Patient-defined Active Disease (n = 1018)
PRO2 Individual Components (UC)				
Rectal Bleeding, n (%)				
No blood in stool	633 (63)	372 (37)	NA	NA
Blood less than 50% of time	32 (15)	176 (85)	NA	NA
Blood 50% or more of time	3 (3)	100 (97)	NA	NA
Stool Frequency, n (%)				
Less stool than normal	39 (46)	45 (54)		
Normal number of stools	537 (75)	181 (25)	NA	NA
1-2 stools more than normal	62 (25)	190 (75)	NA	NA
3-4 stools more than normal	24 (17)	120 (83)	NA	NA
5 or more stools more than normal	6 (5)	112 (95)	NA	NA
PRO3 Individual Components (CD)				
No. soft stools on average, M (SD)			0.9 (1.6)	2.7 (2.8)
Abdominal Pain, n (%)				
None	NA	NA	740 (69)	327 (31)
Mild	NA	NA	166 (28)	424 (72)
Moderate	NA	NA	22 (9)	229 (91)
Severe	NA	NA	1 (3)	38 (97)
General Well-being, n (%)				
Generally well	NA	NA	746 (68)	353 (32)
Slightly below par	NA	NA	149 (28)	385 (72)
Poor	NA	NA	26 (12)	199 (88)
Very poor	NA	NA	6 (8)	68 (92)
Terrible	NA	NA	2 (13)	13 (87)
PRO3, Cutpoints^a				
Remission	NA	NA	813 (66)	413 (34)
Mild	NA	NA	90 (26)	255 (74)
Moderate	NA	NA	23 (7)	322 (93)
Severe	NA	NA	0 (0)	6 (100)
Current Medications, n (%)				
Current Prednisone Use	30 (19)	129 (81)	25 (16)	132 (84)
Current Opioid Use	8 (22)	29 (78)	8 (10)	73 (90)
IBD Care in the past 6 months, n (%)				
Hospitalization	18 (19)	76 (81)	25 (17)	123 (83)
Emergency Department	29 (26)	83 (74)	25 (15)	146 (85)
Health Confidence, n (%)				
7 or above	572 (66)	297 (34)	830 (63)	494 (37)

^aPRO3 cutpoints correspond to the Crohn's Disease Activity Index cutpoints for mild, moderate, and severe disease. NA indicates not applicable.

the individual components of the PRO measures, patients reported remission even while experiencing greater stools than normal and mild symptoms, which would be classified as active disease based on PROs. Therefore, our findings align with studies in which remission is defined as a decrease in symptoms,^{10,11} not necessarily symptom resolution.^{8,9,13} Furthermore, patient-defined remission may incorporate

other factors that are important to patients such as the impact on activities of daily living or social implications.²⁸

Disease duration was strongly associated with discordance between patient-reported and PRO remission. Patients who were recently diagnosed were more likely to self-report active disease despite being in remission based on PROs, whereas those with a longer disease duration were more

Table 4. Multivariable logistic regression models for discordance among patients with remission on PROs, stratified by disease type.^a

	UC	CD
	OR (95% CI)	OR (95% CI)
Male gender (ref: female and other)	0.9 (0.6-1.4)	1.1 (0.8-1.4)
IBD duration (ref: >15 years)		
<5 years	2.0 (1.2-3.3)	1.5 (1.0-2.2)
5-10 years	0.9 (0.5-1.5)	1.1 (0.7-1.5)
11-15 years	0.7 (0.4-1.5)	1.0 (0.7-1.5)
Current prednisone use	1.5 (0.6-4.0)	3.6 (1.8-7.2)
Current opioid use	1.4 (0.4-5.1)	4.4 (1.6-12.1)
Hospitalization in the past 6 months	3.2 (0.8-13.1)	1.0 (0.5-2.2)
Emergency department visit in the past 6 months	1.0 (0.3-2.8)	3.2 (1.5-6.9)
Health confidence: 7 or above	0.4 (0.2-0.6)	0.2 (0.2-0.4)

^aOdds ratios are the odds of discordance. Discordance is defined as patient-reported active disease despite remission based on PROs. Abbreviations: IBD, inflammatory bowel disease, OR, odds ratio; CI, confidence interval; PRO, patient-reported outcomes, UC, ulcerative colitis, CD, Crohn's disease, ref, reference group.

Table 5. Multivariable logistic regression models for discordance among patients with active disease on PROs, stratified by disease type.^a

	UC	CD
	OR (95% CI)	OR (95% CI)
Male gender (ref: female and other)	1.2 (0.7-1.9)	1.2 (0.8-1.9)
IBD duration (ref: >15 years)		
<5 years	0.9 (0.5-1.7)	0.3 (0.2-0.6)
5-10 years	1.3 (0.7-2.5)	0.7 (0.4-1.3)
11-15 years	1.5 (0.7-2.0)	0.7 (0.4-1.2)
Current prednisone use	0.4 (0.2-0.8)	0.4 (0.2-0.97)
Current opioid use	0.7 (0.2-3.2)	0.2 (0.1-0.9)
Hospitalization in the past 6 months	2.5 (0.8-7.9)	0.6 (0.2-1.9)
Emergency Department visit in the past 6 months	0.5 (0.2-1.7)	0.6 (0.2-1.5)
Health Confidence: 7 or above	4.8 (2.9-7.9)	4.3 (2.8-6.8)

^aOdds ratios are the odds of discordance. Discordance is defined as patient-reported remission disease despite active disease based on PROs. Abbreviations: IBD, inflammatory bowel disease, OR, odds ratio; CI, confidence interval; PRO, patient-reported outcomes; UC, ulcerative colitis; CD, Crohn's disease; ref, reference group.

likely to report being in remission despite the continuation of symptoms. Patients with a shorter disease duration may be less familiar with the signs and symptoms that constitute active disease. Yet as disease duration increases, patients may be more willing to tolerate a greater number of symptoms and still consider themselves in remission.¹¹ A cross-sectional survey of patients' understanding of the terms *flare* and *remission* found the majority of patients have a symptom-focused understanding of disease flares and use self-management practices such as increasing sleep/rest, changing diet, and increasing medications.²⁹ Furthermore, in alignment with our

results, a subset of patients report persistent, mild symptoms during remission.²⁹ Therefore, additional research is needed on the complex interplay between the way patients define remission, how that impacts their self-management, and how this relationship changes over time.

A factor that was significantly associated with discordance across all models was health confidence. Health confidence, similar to self-efficacy, refers to patients' confidence in controlling and managing their health problems related to IBD.^{21,30} A cross-sectional study among 207 IBD patients found that lower-self efficacy was associated with more anxiety, productivity loss, and disability.³¹ Patients who are in remission based on PROs who consider themselves to have active disease may need additional training or support to obtain the confidence to more effectively manage their disease. Yet, patients with PRO-defined active disease who self-reported remission were also more likely to report higher confidence. It could be that patients with higher confidence are more comfortable managing their disease despite experiencing increased symptoms, although this hypothesis should be tested in future work.

Among CD patients, recent ED visits, prednisone, and opioid use were associated with discordance. Patients with CD in PRO-defined remission were more likely to consider themselves as having active disease if they had an ED visit within the past 6 months; this may indicate the patient is experiencing symptoms that are not included in the PRO. Discordance in patients on prednisone highlights the complexity of disease activity definitions inasmuch as some definitions of remission include steroid-free remission, whereas others do not.^{5,32} If the patient's goal is steroid-free remission (ie, being in remission without steroids), then a discrepancy between PRO-defined remission and patient-defined remission would be expected. The reason this was primarily observed in CD may be due to steroids leading to an immediate improvement in quality of life³³. Although quality of life is included in the PRO3 for CD, it is not in the PRO2 for UC. Discordance related to opioids may be due to the fact that opioids are masking abdominal pain symptoms in PRO3 for CD³⁴ but not stool frequency and rectal bleeding in PRO2 for UC. Patients who do not experience abdominal pain while using opioids may not consider themselves to be in remission or perceive their disease is not under control due to the need for opioids.

This study reports on the use of a simple patient-reported remission measure: a yes/no question assessing patients' views. Yet, limitations exist in this secondary data analysis. The data set did not include factors such as health literacy, race/ethnicity, and socioeconomic status,^{35,36} which may influence patients' self-report of remission. A single-day PRO value may not capture PRO remission, as the original PRO2 and PRO3 measures were originally developed from 3- and 7-day averages, respectively.^{6,7} Additionally, differences exist in the timing of the various measures that could have contributed to discordance. Patients in IBD Qorus were recruited from specialty clinics and may have more severe disease, as well as greater awareness of IBD compared with the general IBD population. Data were obtained from electronic surveys collected for quality improvement. Therefore, selection bias may have occurred, in which highly motivated patients who are more engaged in their care may have been more likely to complete the survey. Lastly, due to the small sample of PGA reports, the study had limited power to evaluate the relationship between patient-reported

remission and PGA, and the underlying factors contributing to this discordance could not be examined.

Conclusion

Patient-defined remission differs from PRO and PGA measures of remission. Incorporating a single yes/no question to assess patients' views of their remission status may prompt further discussion to learn about patients' priorities. A prior study highlighted that among patients with IBD, the most often prioritized goals and concerns were related to symptoms and disease activity.¹⁸ These goals were related to gastrointestinal symptoms but also systematic symptoms such as depression, fatigue, musculoskeletal pain, and others. Asking patients about whether they are in remission in combination with discussing their main concerns can promote a patient-centered approach to IBD management. The identification of factors associated with discordance between patient-defined remission and PROs could aid clinicians in shaping the discussion they are having about achieving remission as part of the shared decision-making process.

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IBD Qorus group collaborators: IBD Qorus Group collaborators: Ziad Younes (Gastro One, Germantown, TN), Mark C. Mattar (Medstar-Georgetown, Washington, DC), Mark Metwally (University of Chicago, Chicago, IL), Frank Scott (University of Colorado Anschutz Medical Campus, Aurora, CO), Arthur Ostrov (Saratoga-Schenectady GI Associates, Saratoga, NY), David T. Rubin (University of Chicago, Chicago, IL), Mark Gerich (University of Colorado Anschutz Medical Campus, Aurora, CO), Donna Gerner (Saratoga-Schenectady GI Associates, Saratoga, NY), Erica Heagy (The Oregon Clinic, Portland, OR), Eugene Nelson (The Dartmouth Institute for Clinical Practice and Health Policy, Lebanon, NH), Megan Holthoff (The Dartmouth Institute for Clinical Practice and Health Policy, Lebanon, NH), David Hudesman (NYU Langone Medical Center, New York, NY), Ridhima Oberai (Crohn's and Colitis Foundation, New York, NY), Christopher Almario (Cedars-Sinai, Los

Angeles, CA), Harry Bray (The Oregon Clinic, Portland, OR), Damara Crate (Dartmouth-Hitchcock Medical Center, Lebanon, NH), Jason K. Hou (Baylor College of Medicine, Houston, TX), Donald Lum (The Oregon Clinic, Portland, OR), Siddharth Singh (University of California San Diego, San Diego, CA), Rose Arrieta (Northwestern University, Chicago, IL), Andrea Banty (Cedars-Sinai, Los Angeles, CA), John Betteridge (Regional GI, Lancaster, PA), Jessica Carron (Dartmouth-Hitchcock Medical Center, Lebanon, NH), Aline Charabaty (Johns Hopkins Medical Center, Baltimore, MD), Michael Danielewicz (Gastroenterology Associates, Inc, Providence, RI), Josh Deitch (Cedars-Sinai, Los Angeles, CA), Francis Farraye (Mayo Clinic, Jacksonville, FL), Helen Fasanya (Midwest Gastroenterology Associates, Omaha, NE), Ann Flynn (University of Utah Health, Salt Lake City, UT), Christina, Ha (Cedars-Sinai, Los Angeles, CA), Lia Kaufman (Spectrum Health, Grand Rapids, MI), Nirmal Kaur (Henry Ford Medical Group, Detroit, MI), Kristi Kearney (University of Chicago, Chicago, IL), Alice M. Kennedy (The Dartmouth Institute for Health Policy & Clinical Practice, Lebanon, NH), Betty Kim (The Oregon Clinic, Portland, OR), Michelle, Kwon (Gastroenterology Associates, Inc, Providence, RI), Helen Le (University of California, San Diego, San Diego, CA), Carrie Mize (Gastro One, Germantown, TN), Emily Morgan (Dartmouth-Hitchcock Medical Center, Lebanon, NH), Linda Morris-McCoy (Spectrum Health, Grand Rapids, MI), Alexis Oonk (University of Colorado, Aurora, CO), Teresa Pashby (Gastro One, Germantown, TN), Victoria Rai (University of Chicago, Chicago, IL), Swapna Reddy (The Oregon Clinic, Portland, OR), Kami Roake (University of Utah, Salt Lake City, UT), Richa Shukla (Baylor College of Medicine, Houston, TX), Gaurav Syal (Cedars-Sinai, Los Angeles, CA), Cindy Traboulsi (University of Chicago, Chicago, IL), Quin Turner (Dartmouth-Hitchcock Medical Center, Lebanon, NH), John Valentine (University of Utah Health, Salt Lake City, UT), Raluca Vrabie (NYU Langone, New York, NY), Trisha Walker (Shreveport Gastroenterology), Julie Weatherly (Baylor College of Medicine, Houston, TX), Emmanuelle Williams (Penn State Health, State College, PA), Laura Yun (Northwestern University, Chicago, IL), and Tim Zisman (Virginia Mason Medical Center, Seattle, WA).

Conflicts of Interest

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