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Patient Understanding of “Flare” and “Remission” of Inflammatory Bowel Disease

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Abstract

Patients with inflammatory bowel disease have adopted medical jargon terms of “flare” and “remission,” but what they mean by these terms is ill-defined and may have implications for nurse–patient communication and treatment expectancy. The aim of this study was to elicit patients’ understanding of “flare” and “remission.” Individuals with self-reported inflammatory bowel disease were recruited through social media. A web-based survey, with closed and open-ended questions, was administered. Conventional content analysis was used to evaluate respondents’ perceptions of jargon terms. A word cloud was generated to augment analysis by visualization of word use frequency. A majority of the 34 respondents had a symptom-focused understanding and described these terms as alternating states. Various symptoms were understood to signify “flare,” which was largely attributed to lifestyle factors. Corroborated by the word cloud, there was rare mention of inflammation or tissue damage. This study demonstrates that an understanding of “flare” and “remission” by patients with inflammatory bowel disease is largely symptom-based. The role of inflammation, medication failure, and targets of inflammatory bowel disease treatment beyond symptom control are not currently well known to patients with inflammatory bowel disease. To create a shared understanding of symptoms and treatment goals between the patient and the nurse, patient education on emerging expectations of inflammatory bowel disease care should be prioritized.

Ulcerative colitis and Crohn disease, known collectively as inflammatory bowel disease (IBD), are chronic, inflammatory conditions of the gastrointestinal tract with several disabling symptoms that cause significant morbidity and can negatively impact productivity and quality of life (Ganz, Sugarman, Wang, Hansen, & Hakan-Bloch, 2016; Zand et al., 2015). The incidence of IBD is increasing, particularly among young people, leading to an increase in IBD-related use of health services (Gajendran et al., 2016; Kaplan & Ng, 2017; Molodecky et al., 2012). The estimated total annual financial burden of IBD in the United States is between \$14.6 billion and \$31.6 billion (Mehta, 2016).

Background

The introduction of immune-suppressive biological agents for management of IBD has resulted in major shifts in IBD care. First, IBD care has largely moved away from the hospital to the outpatient setting, underscoring the importance of nurse specialists in improving access, providing medical care, and optimizing patient self-management (Greveson & Woodward, 2013). Second, therapeutic goals have shifted from a focus on symptom amelioration to the goal of healing the injured intestinal lining and stopping the progression of damage (Colombel & Mahadevan, 2017). In other words, there is now an expectation that patients with IBD can live relatively normal, healthy lives despite having a chronic condition as long as they have access to early, effective therapies.

Nurse professionals specializing in IBD care are often the first point of contact and counseling for IBD patients. One of the primary challenges that nurses face in caring

for IBD patients, whose conditions are often diagnosed during adolescence or young adulthood, is to foster up-to-date and developmentally appropriate illness knowledge despite ever-changing medical, surgical, and self-management demands (Greveson & Woodward, 2013; Peters, 2014). A shared understanding of the patient's illness and goals of treatment between the patient and the care provider is critical to achieving important outcomes such as medication adherence and appropriate utilization of healthcare resources (Street, Makoul, Arora, & Epstein, 2009; Zolnierak & Dimatteo, 2009).

A conceptual underpinning to this idea of a shared understanding between the patient and the nurse is provided by Peplau's Developmental Stages of Nurse-Client Relationships, which focus on strengthening the proper interpretation of a patient's symptoms to increase the likelihood of appropriate nursing assessment, intervention, and treatment (D'Antonio, Beeber, Sills, & Naegle, 2014), including reducing the risk of overtreatment. To achieve this shared understanding, the nurse professional needs to understand what patients truly mean by the language they use to describe their symptoms.

The words patients use to describe their symptoms, their understanding of their disease, and treatment goals can all, in turn, be affected by word choice during clinical interactions (Beck, Daughtridge, & Sloane, 2002). For patients with IBD, knowledge of their disease and treatment goals is derived primarily from their healthcare providers (Cima et al., 2007). Therefore, the use of medical jargon by providers can influence patients' comprehension of disease, its mechanisms, and, indirectly, treatment goals. A salient example may be provided by the terms "flare" and "remission." These terms are medical jargon used commonly by IBD nurses and physicians and are now well-established in the patient's day-to-day language. However, what a patient means by "flare" and "remission" of IBD is ill-defined and not systematically documented. Integrating nursing clinical knowledge with an understanding of what patients mean when they use these terms will allow for better nurse-patient communication and building of a shared understanding of IBD.

This study aims to describe patient comprehension of the medical jargon terms "flare" and "remission" and document their knowledge of IBD by investigating their perceptions of factors that define and influence "flare" and "remission."

Material and Methods

In this study, a web-based survey was undertaken to elicit patients with IBD understanding of their disease, including the terms "flare" and "remission." Between July and August 2015, individuals with a self-reported diagnosis of IBD and a self-report of current medical therapy for IBD were recruited using snowball sampling techniques through social media websites (Facebook, Twitter) and through websites of IBD support groups (www.girlswithguts.org, www.thegreatbowelmovement.org).

A short description of the study and a link to the anonymous, web-based questionnaire were provided on these websites. The questionnaire was developed by the multidisciplinary research team, including a nurse IBD specialist, gastroenterologists, a health psychologist with expertise in IBD, and with guidance from existing literature (Chapman, Abraham,

Jenkins, & Fallowfield, 2003; LeBlanc et al., 2014; Peckham, 1994; Pieterse, Jager, Smets, & Henselmans, 2013; Wiener, Gould, Woloshin, Schwartz, & Clark, 2013).

The questionnaire consisted of closed and open-ended items. Closed-ended items included demographic and disease-specific variables, such as diagnosis, disease duration, and medication use. Seven open-response items assessed participants' understanding of the terms "flare" and "remission" (Appendix 1, see Supplemental Digital Content 1, available at: <http://links.lww.com/GNJ/A44>). Given the sampling technique and web-based format, no information was collected on nonresponders.

Data Analysis

Content analysis using conventional approach was used to analyze responses to open-ended questions (Hsieh & Shannon, 2005). Qualitative methodology was used because it can be effective in generating coherent hypothesis and explanations for complex social and experiential phenomena encountered by providers and consumers of healthcare where clinical insight is limited (Giacomini & Cook, 2000).

Three independent coders (I.T., S.B., and A.B.), each with a strong background and training in qualitative research methods, coded the open-ended responses. Responses were iteratively analyzed, initially with open coding, to identify emerging themes and generate a preliminary codebook. Each coder independently coded all responses. Coders met weekly to compare codes and to collaboratively refine the codebook. The codebook was modified, and revised codes were applied to responses until thematic saturation was reached. Discrepancies were reconciled through consensus during weekly meetings (Creswell, 2007). Coded data were analyzed within and across cases to develop prominent themes. Identification of themes was based on (1) frequency of identification and (2) whether the theme was found across various items/questions. Qualitative survey responses were entered into NVivo 10 (QSR International Ltd., 2012) to facilitate coding and analyses.

Word cloud generation, a method used to visualize textual data, is being increasingly used in clinical research as a quick and practical method to provide a synopsis of main themes in textual data without bias from the research team. In a word cloud, font size expresses the frequency of use of different words, with larger font size representing a higher frequency of use (Gill & Griffin, 2010; Richardson, Grose, Nemes, Parra, & Linares, 2016). A word cloud was generated using NVivo 10 (QSR International Ltd., 2012). During word cloud generation, the 100 most frequently used words with a minimum length of three characters were queried. Similar terms with different stems ("take" and "taking") were grouped together. "Flare," "remission," prepositions, and other Common English words ("get," "just," "put") were removed from the query.

Ethical Considerations

This study had unidentified participants and was exempt from institutional review board review.

Findings

Participant Characteristics

Thirty-four respondents completed all survey items. The respondents were mostly female, and their mean age was 33 years (Table 1). A majority (73.5%) reported having Crohn disease. About half of the respondents were prescribed an immune-suppressive medication in the current or past year to treat IBD. Nineteen other respondents opened the survey link but were either excluded (4—not attempted; 1—not diagnosed with IBD; 8—not currently treated for IBD) or had incomplete responses (6—mean age 40.7 years, 14.3% female, 42.9% with Crohn disease, 57.1% with ulcerative colitis). All 34 respondents reported being familiar with the terms “flare” and “remission” as related to IBD. Almost all respondents felt “flares” were expected in IBD, including in their own disease course.

Themes

Themes were categorized into four broad domains that described the key aspects of respondents’ perceptions of “flare” and “remission”: definition of flare, causes of flare, the impact and management of flare, and the definition of remission.

Domain 1: Definition of Flare—A symptom-focused understanding of “flare” emerged as the major theme (Table 2). Respondents broadly perceived the term “flare” to be an experience of symptoms viewed as being characteristic of their IBD. For example, a 22-year-old woman with Crohn disease described flare as “a severe and sudden increase in symptoms, including extreme pain, bleeding, and diarrhea.” A rich description of symptoms perceived as demonstrative of “flare” emerged and included abdominal pain, diarrhea, fecal urgency, and rectal bleeding. Fatigue and swollen and painful joints were also very frequently described. Less commonly mentioned symptoms included weight loss, nausea, bloating and gas, bowel obstruction, mucus in stools, and fevers.

For most respondents, “flare” implied a period of sustained and lingering gastrointestinal symptoms described earlier that alternates with “remission” in a cyclical pattern. A subset of respondents used the term “active” to describe symptoms associated with flare. For example, a 40-year-old man with ulcerative colitis defined flare as “when active symptoms appear.”

An inflammation-based understanding was noted among a small subset of respondents. A 52-year-old man with ulcerative colitis described “flare” as “actual inflammation—not just diarrhea for a day after you ate food that tends to cause diarrhea.” Only two respondents discussed the need to confirm the presence of inflammation with objective data such as an endoscopy or laboratory findings in order to confirm a “flare.”

Domain 2: Causes of Flare—Respondents perceived lifestyle-related factors as a major cause of “flare,” with stress, diet, and other lifestyle choices highlighted most frequently (Table 3). A 31-year-old woman with ulcerative colitis reported, “So many reasons [for flare]! Stress, environment, medications, weather and sometimes they just happen.” A few respondents, however, noted the lack of definitive link between diet, stress, and IBD flares.

Medication-related understanding of disease mechanisms emerged as a separate theme, including loss of efficacy of medications or effect of medication non-compliance. A very small minority of respondents commented on the role of inflammation and tissue damage in causing a flare. For example, a 39-year-old woman with Crohn disease reported, “My immune system wins the fight ... causing inflammation and damage to my body.”

Domain 3: Impact and Management of Flare—The impact of “flare” extended across respondents’ physical, mental, and emotional well-being, their quality of life, and the lives of friends and family (Table 4). Respondents predominantly highlighted fatigue, sleep disruptions caused by going to the bathroom frequently, and anorexia as a result of a flare. The emotional impact of a self-defined “flare,” with significant component of anxiety, depressed mood, fear, and poor quality of life, was highlighted by almost all respondents. The impact of “flare” on social interactions, especially that of burdening loved ones, was also frequently brought up.

Most respondents discussed contacting their gastroenterologist as a first step in management of “flare,” via telephone, using a patient portal, or during a clinic visit (Table 5). A subset of respondents believed that resolving a flare would require escalation of medical care with change of medication, emergency care, hospitalization, and bowel surgery. However, most respondents reported self-care practices as being their major response to onset of symptoms thought to be consistent with “flare.” Congruent with the majority of respondents’ symptom-focused understanding of flare and belief that lifestyle factors are causative of flare, they discussed self-management practices such as changing their diet, increasing rest/sleep, and self-directed increased intake of over-the-counter medications (such as vitamin supplements, pain medications) or prescription medications. “Change my diet—eat very basic bland foods that I know don’t upset my stomach,” reported a 23-year-old woman with Crohn disease as response to “flare.”

Domain 4: “Remission”—As with their understanding of the term “flare,” most respondents viewed the term “remission” from a symptom-focused perspective (Table 6). Remission was understood as an opposite to and alternating with “flare.” Most respondents felt that remission involved an extended period of time without experiencing significant IBD symptoms. A 23-year old woman with Crohn disease described “remission” as “no signs of active disease and not being on any biologics. However, my doctors would consider me in remission even if I was in treatment and had no signs of active disease,” highlighting the expectation of some IBD patients that “remission” is indicative of a cure and being off medical therapy.

Although most respondents expected to be asymptomatic during remission, a subset reported persistent, but short-lasting and mild symptoms, such as fatigue, abdominal pain, and occasional loose stools. A few respondents highlighted tissue damage and continued symptoms from structural damage, such as bowel narrowing caused by IBD. A minority of respondents outlined an inflammation-based understanding with healed mucosa on endoscopy and normalized laboratory markers as demonstrative of “remission.” “Remission means no evidence of inflammatory response—i.e., Blood work normal,” stated a 40-year-old woman with Crohn disease.

Word Cloud Analysis

The word cloud analysis (Figure 1) demonstrated that “symptoms” and “pain” were the most frequently reported terms. Conversely, “inflammation” occurred rarely in the textual data.

Discussion

This exploratory, qualitative study provides a nuanced description of patients’ IBD-related symptoms, their use of jargon terms, and, through these, their understanding and expectations of IBD care. To the best of our knowledge, this is the first study to document what patients with IBD mean by the words “flare” and “remission.” Respondents had a predominantly symptom-focused understanding of these terms, with a strong emphasis on lifestyle factors as being causative and palliative of disease, and an expectation of ongoing cycles of flare and remissions as part of disease course. A word “cloud analysis” augments these findings by highlighting that symptoms and related terms were used most frequently with a relative lack of use of “inflammation.”

In the event that a patient experiences particular symptoms and suspects a “flare,” it is the role of the nurse to triage their condition, effectively communicate potential causes, and develop a management plan. Successfully completing such steps will provide the patient with a better understanding of their symptoms, identify other potential causes for their experienced symptoms other than IBD, increase their pathophysiological knowledge of IBD, and potentially improve important health outcomes. Indeed, nurse specialists are at the forefront of IBD management and have demonstrated reduction in emergency department use and unscheduled clinic visits and improvement in patient satisfaction and quality of life (Amo et al., 2016; Coenen et al., 2017). However, all this can only be facilitated if there is a shared understanding of IBD between the patient and the nurse.

This study has important implications for nurse specialists, specifically by addressing nurse–patient communication and by providing a detailed map of IBD patients’ illness representations. These lay beliefs are complex schemas, derived from personal experiences, which influence the way an individual perceives disease, understands symptoms, and copes with illness (Hale, Treharne, & Kitas, 2007; Sherwin, Leary, & Henderson, 2017).

Lay beliefs are extremely important in a patient’s response to treatment proposed by healthcare providers but are rarely completely congruent with biomedical concepts of disease (Donovan, Blake, & Fleming, 1989). In this study, patients understood IBD through the lens of numerous gastrointestinal and systemic symptoms, lifestyle factors, and the profound psychosocial impact of IBD. In accordance with the identification and working phase of Peplau’s Developmental Stages of Nurse–Client Relationships theory, acknowledging patients’ lay beliefs about IBD and incorporating this knowledge into nurse–patient communication will allow for a shared understanding of disease between the patient and the nurse and facilitate expedient and high-quality care.

This study provides insights into the effect of medical jargon on a patient’s understanding of his or her illness and treatment expectations. It is documented that healthcare providers use unclarified medical jargon terms very frequently during clinical encounters, especially while

making treatment recommendations. This ubiquitous use of jargon can negatively impact patients' disease comprehension rates and can even be perceived as being unprofessional by patients (Berman et al., 2016; Castro, Wilson, Wang, & Schillinger, 2007; Chou et al., 2017).

In the context of IBD, the frequency of use or true definition of medical jargon terms, "flare" and "remission," is not known. However, this study documents that most patients with IBD are very aware of these terms and use them frequently. The findings of this study are congruent with the traditional focus of IBD management, which is the primary goal of symptom amelioration by using a decision-making process based predominantly on a patient's symptoms. Patients' understanding of IBD disease mechanisms seemed to be similarly affected by such a symptom-focused approach, with scarce knowledge of role of inflammation and tissue damage, and lifestyle factors (such as stress, sleep, and diet) considered primary in disease pathogenesis.

However, it is now recognized that reducing symptoms does not necessarily halt the progression of IBD and associated complications (Colombel, Narula, & Peyrin-Biroulet, 2017). Given this, and the known discordance between gastrointestinal symptoms and disease markers, aiming to resolve evident inflammation on endoscopic examination has emerged as a major treatment goal for patients with IBD. This endpoint is referred to as mucosal healing.

This paradigm shift in IBD care has expanded clinicians' management approach from a symptom-based approach of ascertaining remission by patient report to one of confirming the presence of inflammation through endoscopy, imaging, or laboratory testing. This approach has made the terms "flare" and "remission" much less subjective and disease course more predictable. However, only nine respondents discussed the role of inflammation in "flare" or "remission."

Although this subset of respondents was similar to the overall group in terms of diagnosis, disease duration, and medication use, they had higher rates of agreement with their healthcare team on the definition of "flare" as ascertained by a question asking them whether their definition of "flare" was similar to their healthcare team's. Triangulation of this agreement is not possible, given that this study did not involve clinicians and, to the best of our knowledge, there is a lack of literature eliciting clinicians' perception of these terms. However, this may indicate that a shared understanding of IBD and treatment goals between the patient and the clinician has been achieved in this subset of patients.

Based on the study results, the role of the nurse IBD specialist in triaging the initial symptom complaints is vital to paving a clearer pathway to patient understanding of their own symptoms and disease. As such, one of the main goals of nurse IBD specialists should be to communicate to patients the role of inflammation, the disconnect between symptoms and inflammation, the importance of confirmatory testing, and targeting tissue damage as the goal for therapy. This would facilitate a shift in the patient's understanding of their disease from symptom-focused to inflammation-predominant.

A few respondents did demonstrate growing awareness about possible lack of concordance between gastrointestinal symptoms and tissue damage from inflammation. This

understanding would be most beneficial for patients who are in clinical remission but with ongoing, silent mucosal inflammation where continued compliance with medications and ongoing surveillance is essential.

About 90% of respondents in this study expect to have “flares” of their disease despite a majority already being on immune-suppressive biological medications. Although this may represent an experience of poor disease control despite being on highly effective medications, given that newer and more effective medications are now already available and that there has been rapid development of strategies to maximize their ability to heal the mucosa, patients can expect wellness and freedom from the flare–remission cycle. This treatment expectancy could be another target to which IBD treatments are calibrated.

Our findings are also important for researchers and policy makers who aim to study the link between patient understanding of disease and clinical and healthcare utilization outcomes. Web-based patient commentaries have been used in other studies to examine crucial aspects of patient care that cannot be captured in conventional quantitative healthcare satisfaction and quality surveys (Lopez, Detz, Ratanawongsa, & Sarkar, 2012). Web-based, open-ended surveys of subjects with chronic diseases are increasingly being used in IBD to assess complex, experiential topics such as quality of life, body image, sexual functioning, and shared decision-making models (Muller, Prosser, Bampton, Mountifield, & Andrews, 2010; Purc-Stephenson, Bowlby, & Qaqish, 2015; Siegel et al., 2015).

This study has several limitations. Recruitment of participants with self-reported diagnosis of IBD using social media makes this study prone to concerns about accuracy of diagnosis and selection bias. Previous Internet-based IBD studies have demonstrated an accuracy of self-reported IBD diagnosis of more than 95% (Kelstrup, Juillerat, & Korzenik, 2014; Randell et al., 2014). Participants in this study differed compared with a large, well-validated, longitudinal, Internet-based cohort study of individuals with self-reported IBD (the Crohn’s and Colitis Foundation of America Partners—CCFA Partners) (Kappelman et al., 2014). However, the differences between groups, such as younger age, higher percentage with Crohn disease, and on immune-suppressive therapies, indicate that this study population may be sicker and, as such, more likely to consume healthcare resources and interact with nurse professionals. Hence, documenting their perceptions of illness is particularly valuable to improve nurse–patient communication.

Given the small sample size, the issue of generalizability is raised. However, a qualitative analysis of patient beliefs and understanding of illness contributes to generalizable knowledge by being richly descriptive and theme-generating, rather than statistically representative of a specific population. Similarly, qualitative research techniques, with their stress on contextual particularity, do not aim to be reproducible (Patton & Patton, 2002). Because of the anonymous nature of the survey, participants could not be contacted to review or comment further on preliminary conclusions.

Conclusions

Patients comprehend “flare” and “remission” of IBD from a symptom-focused perspective, as alternating states that are expected as part of the cyclical disease trajectory of IBD. Knowledge of the role of inflammation and tissue damage is scarce. As such, patients’ understanding of IBD disease mechanisms and treatment expectations does not yet reflect the emerging therapeutic paradigm of mucosal healing. Nurse specialists can leverage this knowledge to create shared understanding of illness with their patients and foster nurse–patient communication. Further studies are needed to assess how this gap in patient understanding impacts outcomes, including clinical outcomes and health services utilization.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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FIGURE 1.

Word cloud representation of patient understanding of medical jargon terms of “flare” and “remission” in inflammatory bowel disease. Word cloud generated using NVivo 10 (QSR International Ltd., 2012).

TABLE 1.

Respondent Characteristics

Characteristic	Frequency (%) (N = 34)
Gender	
Female	27 (79.4)
Male	7 (20.6)
Age	
Mean (range, standard deviation)	33 (16–56, 10.1)
Residential community	
Urban	8 (23.5)
Suburban	18 (52.9)
Rural	8 (23.5)
Diagnosis	
Crohn disease	25 (73.5)
Ulcerative colitis	8 (23.5)
Indeterminate colitis	1 (2.9)
Duration of IBD (in years)	
Mean (range, standard deviation)	8.4 (0–29 years, 6.2)
Medications	
Prescribed a biologic/advanced therapy in the current or past 1 year ^a	18 (52.9)
Prescribed a steroid in the current or past 1 year ^b	17 (50.0)

Note. IBD = inflammatory bowel diseases.

^aIncludes adalimumab, certolizumab, golimumab, infliximab, natalizumab, and vedolizumab. Also includes cyclosporine, tacrolimus, and thalidomide.

^bIncludes pills, suppositories, enemas, or intravenous preparations of prednisone, dexamethasone, budesonide, and hydrocortisone.

TABLE 2.

“Flare”: Patient Perceptions of Medical Jargon Term in the Context of IBD

Themes	Representative Quote
Symptom-focused understanding	
Experience of symptoms	<p>“More than a normal amount of symptoms, increased numbers of bowel movements, upset stomach and exhaustion.” (Male, 37, CD)</p> <p>“A period when IBD symptoms are uncontrolled or not easily managed by medications.” (Female, 26, UC)</p>
Prolonged duration of symptoms	<p>“A consistent increase in symptoms over several days or weeks, not an isolated spike in symptoms for a day or two.” (Female, 39, CD)</p> <p>“In my opinion, the word ‘flare’ is a prolonged period of increased symptoms. It is not something that comes and passes within a few days.” (Female, 25, CD)</p>
“Active” disease or symptoms	<p>“When your disease is active and more out of control than normal.” (Female, 36, CD)</p>
Cyclic nature of “flare” and “remission”	<p>“Bouts of disease that are more intense than when in remission.” (Male, 27, CD)</p> <p>“Experiencing symptoms, when not in remission.” (Female, 38, UC)</p>
Inflammation-based understanding	<p>“An increase in symptoms that involves a spike in inflammatory response.” (Female, 40, CD)</p> <p>“Having an endoscopy or colonoscopy with biopsy that shows the Crohn’s is active.” (Female, 40, CD)</p> <p>“[I] call my doctor, get scopes done to assure symptoms are from disease.” (Female, 25, CD)</p>

Note. CD = Crohn disease; IBD = inflammatory bowel diseases; UC = ulcerative colitis.

TABLE 3.

“Flare”: Patient Understanding of Causes of “Flare” and Disease Mechanisms

Causes of Flare	Representative Quote
Lifestyle-related factors	
Stress	<p>“If I have too much stress in my life with no relief, am not getting enough sleep ... or I’m not taking enough time to relax, it seems likely I’ll get a flare.” (Female, 31, CD)</p> <p>“I have noticed that I flare up around finals time in school which is rather counterproductive.” (Female, 23, CD)</p>
Diet	<p>“Eating irritating foods.” (Female, 26, CD)</p> <p>“Sometimes due to foods I eat.” (Female, 40, CD)</p>
Seasons, weather, environmental factors	<p>“Seasonal factors. My symptoms often begin in the fall.” (Female, 26, UC)</p> <p>“Seems to be a seasonal thing.” (Male, 51, CD)</p>
Sleep disturbance	<p>“Excessive travel, lack of sleep.” (Male, 29, CD)</p> <p>“Not getting enough rest.” (Female, 40, CD)</p>
Medication-related factors	
Lack of medication adherence	<p>“This can happen because I’m not as adherent to the regimen as I should be.” (Female, 39, CD)</p>
Lack or loss of medication response	<p>“Most often, I think it’s because a medication program isn’t having the intended effect or has lost its effect.” (Female, 22, CD)</p>
Inflammation-related factors	
Immune dysregulation	<p>“When the body attacks itself for no good reason.” (Male, 40, UC diagnosis)</p> <p>“When the body’s immune system identifies part(s) of the small and/or large intestine as foreign and begins to stage an attack.” (Female, 23, CD)</p>
Tissue damage	<p>“Inflammation and damage to my body.” (Female, 39, CD)</p>
Microbiome dysregulation	<p>“Good vs. bad bacteria in the gut/intestines.” (Female, 29, CD)</p>
Other themes	
No identifiable reason/random	<p>“I think it happens for no apparent reason. One day I might be fine, and the next I feel horrible for weeks on end.” (Female, 25, CD)</p> <p>“[Flares] often happen for no identifiable reason.” (Female, 39, UC)</p>
Genetic susceptibility	<p>“Combination of stress, certain foods, genetics.” (Female, 47, CD)</p>
Pain medications	<p>“I have had a flare triggered by pain medications.” (Female, 39, UC)</p>

Note. CD = Crohn disease; IBD = inflammatory bowel diseases; UC = ulcerative colitis.

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“Flare”: Patient Strategies for Management and Resolution

TABLE 4.

Theme	Representative Quote
Lifestyle changes	
Rest	“Increase amount of probiotics and vitamins I take, modify diet, talk to doctor.” (Female, 26, UC)
Change in diet	“Rest, tell doctors, eat more conservatively.” (Female, 25, CD) “Do not eat and/or eat rice, potatoes, noodles; rest, stay home.” (Female, 47, CD)
Escalation of medical care	
Need for medications (including pain medications)	“Wait a few days if it’s not bad to see if it goes away. Consider my medication schedule because if I am due for an infusion, that’s probably an indication.” (Female, 31, UC) “I am immediately put on either a suppository or prednisone.” (Female, 16, UC)
Need for further testing	“Go to GI and have tests performed.” (Male, 20, CD) “Get scopes done to assure symptoms are from disease.” (Female, 25, UC) “Having an endoscopy or colonoscopy with biopsy that shows that Crohn’s is active.” (Female, 40, CD)
Need for inpatient medical services: Emergency department, hospitalization, surgery	“I get very afraid that they only real solution to the flare is surgery.” (Female, 22, CD) “Require hospitalization for pain management and nutritional intervention.” (Female, 22, CD)

Note. CD = Crohn disease; IBD = inflammatory bowel diseases; UC = ulcerative colitis.

“Flare”: Impact on Patients’ Lives

TABLE 5.

Theme	Representative Quote
Physical impact	
Fatigue	<p>“I am tired and generally homebound and often stuck in bed and near a bathroom.” (Female, 39, UC)</p> <p>“The most impactful part is the lack of energy. I generally try to maintain my daily schedule, but by the evening I’m too exhausted to really do anything.” (Female, 25, CD)</p>
Mental/emotional impact	
Anxiety	“[A flare] makes me worry that it will spiral out of control and severely impact my daily life.” (Female, 31, UC)
Depressed mood	“[It] makes the simplest of tasks seem impossible. My self-worth hits rock bottom, I feel useless to my kids and employer.” (Female, 29, CD)
Quality of life	<p>“[I] can’t do things I want to do.” (Female, 56, CD)</p> <p>“[Flare] puts life on hold.” (Male, 40, UC)</p> <p>“Not knowing how long you can stay out in public before you have to find a restroom.” (Female, 47, CD)</p>
Social impact	
Professional activities	<p>“Missed work, money lost from wages, increased costs with medicine, [and] loss of social life.” (Female, 39, CD)</p> <p>“[A flare] makes me less likely to go to work and attend social gatherings.” (Male, 37, CD)</p>
Impact on family and friends	<p>“My kids suffer the most because I am unable to help them with small things like get a drink of water or take them to activities.” (Female, 36, CD)</p> <p>“My family is affected by my IBD as they are constantly worrying about me, making sure I am feeling okay, and trying to help me fight back. They are extremely supportive, but I know that it must take a toll on them and they try their best to not show it.” (Female, 23, CD)</p>

Note. CD = Crohn disease; IBD = inflammatory bowel diseases; UC = ulcerative colitis.

TABLE 6.

“Remission”: Patient Perceptions of Medical Jargon Term in the Context of IBD

Theme	Representative Quote
Symptom-focused understanding	
Cyclic nature of “flare” and “remission”	<p>“Not having a flare or periods of time in between a flare.” (Female, 47, CD)</p> <p>“No flares for an extended period of time.” (Female, 16, CD)</p> <p>“It means you haven’t had a flare for a long time and you mostly feel well.” (Female, 30, UC)</p>
Absence of symptoms	<p>“Where one can have a normal life free from symptoms of the disease.” (Female, 16, UC)</p> <p>“None!” (Female, 31, UC)</p> <p>“I would consider myself in remission when I’m able to live my life without barriers of IBD symptoms.” (Male, 29, CD)</p>
Persistent symptoms	<p>“I was in remission for seven years but yet I had mechanical problems and problems from what the Crohn’s has done to my body.” (Female, 40, CD)</p> <p>“Occasional abdominal pain/bloating, pretty much constant fatigue.” (Female, 30, UC)</p>
Lack of “activity”	<p>“Lack of active disease in the bowel.” (Female, 25, CD)</p> <p>“Time periods when my disease is not active.” (Male, 29, CD)</p>
Inflammation-based understanding	
Mucosal healing	<p>“No active disease as checked by scopes.” (Female, 25, CD)</p> <p>“No inflammation in intestines.” (Female, 31, UC)</p>
Normal investigation	<p>No evidence of inflammatory response—i.e., Blood work is normal.” (Female, 40, CD)</p> <p>“No physiologic markers of disease.” (Female, 39, CD)</p>
Tissue damage	<p>“Pain can be from past damage. EIM can remain although less active.” (Male, 52, UC)</p> <p>“Hopefully none, but diet and lifestyle may still cause symptoms. I have a structure that is scar tissue, so I still may have difficulties with a high volume of food or too much fiber.” (Female, 25, CD)</p>

Note. CD = Crohn disease; IBD = inflammatory bowel diseases; UC = ulcerative colitis.