



# Sociocultural Considerations for Food-Related Quality of Life in Inflammatory Bowel Disease

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## KEYWORDS

- Inflammatory bowel disease • IBD • Sociocultural • Food culture
- Diet-related disparities • Food avoidance • Restrictive eating
- Food-related quality of life

## KEY POINTS

- Food-related quality of life (FRQoL) involves the influence of diet, eating patterns, and food-related anxiety on quality of life.
- Food avoidance and restrictive eating has been identified as a contributor to reduced FRQoL in inflammatory bowel disease (IBD).
- Sociocultural influences on FRQoL in IBD may include food culture, diet acculturation, diet-related disparities, food insecurity, and diet quality.

## INTRODUCTION

The prevalence of gastrointestinal (GI) disorders has been increasing globally and within minority groups migrating to Western countries from countries that have lower prevalence.<sup>1</sup> The varying environmental, cultural, and religious factors between minority groups may influence the physical and psychosocial lived experience, thus quality of life (QoL) and health-related quality of life (HRQoL), of minority groups living with GI disorders. The severity of symptoms has been shown to be associated with reduced HRQoL in GI disorders.<sup>2–4</sup> Symptoms may include nausea, vomiting, altered bowel habits, gas, bloating, and/or cramping.

When aspects of QoL and mental health are combined with diet, food-related quality of life (FRQoL) emerges as a factoring concept in the nutrition and psychosocial

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evaluations of the patient suffering from GI disorders. FRQoL is the evaluation of how diet, eating patterns, and food-related anxiety influence the QoL of the patient.<sup>5</sup> Patients may implement restrictive food patterns as an effort to alleviate symptoms. Food avoidance and restriction may consequently result in nutritional consequences of unintentional weight loss, nutrient deficiencies, and sarcopenia. Disordered eating may also arise when food avoidance and restriction is prolonged voluntarily by the patient.

In the context of inflammatory bowel disease (IBD), which encompasses Crohn disease (CD) and ulcerative colitis (UC) as a part of immune-mediated continuum of inflammatory diseases, the QoL and HRQoL are found to be significantly reduced in IBD in both children and adults.<sup>6</sup> IBD can include a gamut of GI symptoms such as abdominal pain, rectal bleeding, weight loss, anemia, altered bowel habits, gas, bloating, and cramping. It can result in significant illness via complications of strictures, fistulas, sepsis, and bowel cancers. The QoL is found to be less in those with active disease compared with those in remission and in those with CD compared with those with UC.<sup>7</sup> A lack of social support and lower economic status has been found with greater psychological distress in IBD as well.<sup>8</sup>

Poor FRQoL has been found to be associated with restrictive eating in IBD.<sup>9</sup> A prevalence of food avoidance (28%–89%) and restrictive eating (41%–93%) was identified in patients with IBD.<sup>10</sup> Risk factors associated with loss of FRQoL were associated more so with women, a diagnosis of CD, a presence of active disease, symptom severity, significant misinformation around diet, and worries of having GI symptoms with diet.<sup>11</sup>

The prevalence of pediatric and adult IBD in the United States is estimated to be 77.0 and 478.4 per 100,000 individuals in 2016, respectively.<sup>10</sup> More recent data estimate the prevalence in the United States of IBD to be approximately 3.1 million (1.3% of its population) with a substantially increased prevalence of IBD in non-White races and ethnicities.<sup>12,13</sup> Given that population demographics are changing rapidly, and the United States will soon become a nation of minorities as the majority,<sup>13</sup> sociocultural influences of diet acculturation, food insecurity, and diet-related disparities also become factoring concepts with regard to QoL, HRQoL and thus, potentially FRQoL.<sup>13</sup>

The influence of these elements in IBD on FRQoL beyond food avoidance and restrictive eating is not well-known. The purpose of this review is to primarily discuss current evidence for FRQoL as well as its sociocultural influences in patients with IBD. The perspective of the lived patient experience will be included along with a discussion of future directions for the provision of research and cultural competency.

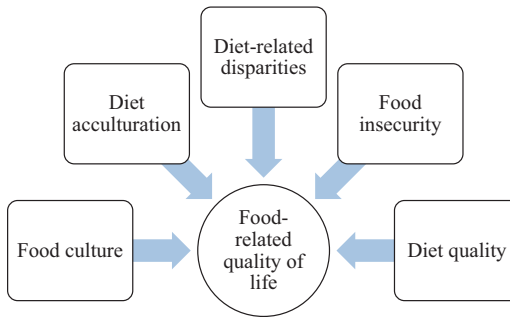
## **SOCIOCULTURAL CONCEPTS FOR FOOD CULTURE**

An introductory discussion of sociocultural concepts because it relates to food culture is imperative to the subsequent discussions of FRQoL (**Fig. 1**).

The term sociocultural has evolved from the concepts behind sociocultural theory. As part of this theory, culture gives humans the tools to adapt intellectually into the culture in which they live.<sup>14</sup> Food is a constituent of that; humans adapt to the food they grew up with as a part of their culture.

### ***Diet Acculturation***

Acculturation of diet may occur with migration and refers to the “*process that occurs when members of a minority group adopt the eating patterns/food choices of the host country.*”<sup>15</sup> Along with adoption of a new way of eating, immigrants may continue some traditional practices of their own food culture as well.



**Fig. 1.** Sociocultural influences to consider for food-related quality of life.

Food is also often a means of expressing and retaining one's identity.<sup>16</sup> That is, people are able to connect to one another in their own culture via food, which creates a sociocultural dynamic around food becoming a vehicle of socialization and human connection. Food culture thereby comprises the sociocultural aspect of eating and includes the “*beliefs, values, and attitudes*” a community may accept around food, acknowledging that practices may vary within communities and religions in the same country. Acceptance of food choices within a culture are determined by biologic cues of taste and smell, repetitive exposure of foods, level of social support, and availability of resources.<sup>17</sup> Food culture may also dictate how food practices are passed through generations from parents to their children. Gender and social roles are defined within a food culture. Expansion of the concept of food culture may also encompass the infrastructure of the food system within a community, which may involve food acquirement, distribution, finances, and eating environment.

### ***Food Insecurity***

Food insecurity refers to “*the household-level condition of limited or uncertain access to adequate and nutritious food,*” and 11.1% of American households have experienced food insecurity in 2018.<sup>18</sup> The populations that may experience food insecurity are the young, racial/ethnic minorities and those who have less household income. The treatment and management of a GI diagnosis using diet can be challenging in the presence of food insecurity.

Affordability determines the level of access to foods of nutritional value that are recommended for a diagnosis. Food insecurity is associated with an increase in visits to the emergency room, hospital admissions, and costs; moreover, food insecurity is largely correlated with poor HRQoL. There is also an association found between food insecurity and risk for depression and anxiety.<sup>19,20</sup> Screening for depression and anxiety is indicated with identification of food insecurity.

### ***Diet-Related Disparities***

Disparities related to diet can be referred to as “*differences in dietary intake, dietary behaviors, and dietary patterns in different segments of the population, resulting in poorer dietary quality and inferior health outcomes for certain groups and an unequal burden in terms of disease incidence, morbidity, mortality, survival, and quality of life.*”<sup>21</sup> The demographics, socioeconomic status, psychosocial, environmental, and cultural characteristics of specific populations influence dietary intake and its related behaviors, which may also contribute to diet-related disparities. Income is a primary socioeconomic contributor to diet-related disparities.<sup>21</sup> The inadequate access to

nutritious foods that come with a higher cost may also contribute to diet-related disparities.<sup>22</sup> Populations facing diet-related disparities may also have higher rates of prevalence, incidence, morbidity, and mortality for chronic diagnoses related to alterations in diet, such as cardiovascular disease, diabetes, and obesity. Diet acculturation is also with the potential to contribute to diet-related disparities.<sup>21</sup>

Diet-related disparities and food insecurity may contribute to less diet quality.<sup>23</sup> Dietary intake of fruits and vegetables in patients of lower socioeconomic status has been found to be less along with reduced intake of vitamin A, B6, calcium, magnesium, and zinc in adults experiencing food insecurity.<sup>24</sup> In children experiencing food insecurity, only fruit consumption was found to be less.

## **INFLAMMATORY BOWEL DISEASE AND FOOD-RELATED QUALITY OF LIFE**

The following discussions will review FRQoL and its sociocultural influences in the realm of IBD.

### ***Sociocultural and Food-related Quality of Life***

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Diet has been identified as an environmental risk factor. Risk for IBD may arise as immigrants that have migrated to a new country undergo a change in lifestyle and environment in their new country. Adoption of the Western diet that is higher in animal protein, saturated fats, processed foods, and lower in fruits, especially in fruits and vegetables, has been implicated in the development of IBD.<sup>25</sup> There are limited studies on how the change in food culture in setting of diet acculturation may influence FRQoL in IBD. A cross-sectional study of 58 adult Hispanic immigrants (29 with IBD after immigration and 29 controls) in the United States found the rates for diet acculturation were similar between those with IBD and in the controls.<sup>26</sup> The patients with IBD here were found to have a greater intake of non-whole grains and less intake from fruits and vegetables in comparison to the controls.

Food insecurity and lack of social support were found in adults with IBD in one study. There is an estimate of 3.1 million adults with IBD living in the United States, in which 12% of the patients reported to experience food insecurity and minimal social support.<sup>27</sup> The results further showed that 19% of patients were concerned that food would run out before being able to buy more and 16% of patients reported that food did run out before obtaining money to buy more. Overall, 1 in 8 patients with IBD has food insecurity and minimal social support. IBD patients found to have food insecurity were significantly more likely to have financial adversity with medical bills. There is, however, no increased use of the emergency room.

Nutrient inadequacies have been associated with loss of FRQoL. A multi-center study of 1576 pediatric and adult patients (aged older than 16 years) evaluated the association between nutrient intake and FRQoL.<sup>28</sup> Questionnaires were distributed to patients to evaluate FRQoL, QoL, distress, fatigue, anxiety, and depression. The European Prospective Investigation into Cancer Food Frequency Questionnaire was used to collect intake data from diet. The results showed that FRQoL was correlated with recurrent active disease and reduced intake of dietary fiber, calcium, phosphorus, and magnesium. Additional studies are warranted to gain understanding of how nutrient inadequacies can also arise in the setting of food insecurity and diet-related disparities.

### ***Symptoms and Food-related Quality of Life***

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Several studies have evaluated FRQoL in adult and pediatric patients with IBD with the FRQoL-29 questionnaire that has been validated for its use in adults with IBD.<sup>29</sup> In a

study of 175 adult patients (80 with irritable bowel syndrome [IBS] and 95 with IBD) showed that symptom severity was the highest predictor for FRQoL in both patient populations.<sup>5</sup> A study of 108 adult patients with IBD completed multiple questionnaires with the FRQoL-29, Harvey Bradshaw Index, Simple Clinical Colitis Activity Index, Nine-Item Avoidant/Restrictive Food Intake Disorder Screen, and the Depression Anxiety Stress Scale-21.<sup>9</sup> The results showed that patients with IBD exhibiting restrictive eating and have active disease were found to have reduced FRQoL. Regardless of the severity of active disease, patients with UC had less FRQoL than patients with CD. The patients with less disease activity and history of prior surgery for IBD were found to have a higher FRQoL. A prospective and cross-sectional single-center study had 60 children and adolescents with CD complete the FRQoL-29 questionnaire to evaluate FRQoL.<sup>30</sup> The results showed that FRQoL was reduced in the patients with CD along with their siblings when compared with controls. Factors of age and nutrition risk were found to be correlated with less FRQoL.

The trial and error process of which foods may serve as triggers to symptoms was also found to reduce FRQoL.<sup>31</sup> Having minimal guidance and less knowledge of how to identify foods may trigger or not trigger symptoms served as a contributing factor to experiencing stress with foods, including lack of pleasure with meals and having fear with eating in social settings. The labor involved with grocery shopping and meal preparation to help plan for meals tailored to IBD also was associated with less FRQoL. Level of support from family for meals was found to vary, which led to eating in isolation for some. To learn of the level of support in diet, it would be beneficial to also learn of family dynamics within a food culture, especially of gender and social roles with diet.

### ***Malnutrition and Food-related Quality of Life***

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Malnutrition in IBD is found in 65% to 75% in CD and 18% to 62% in UC and is correlated with an increase in rates of hospital admissions as well as duration of the hospital stay.<sup>32</sup> Malnutrition involves a constellation of symptoms of decreased nutritional intake, unintentional weight loss, loss of muscle and fat stores, and changes in functional capacity. Within inflammatory contributors, malnutrition can arise based on the segment(s) of the bowel that is (are) involved in active disease. Within social/environmental contributors, practices of restrictive eating as an effort to reduce symptoms or control inflammation can cause malnutrition.<sup>33</sup> Food insecurity can also contribute to malnutrition.<sup>34,35</sup> The early screening of malnutrition will allow timely implementation of interventions for its treatment and management. There are various tools in existence to aid in the identification of malnutrition, such as the Malnutrition Universal Screening Tool and the Subjective Global Assessment.

In IBD, malnutrition has been shown to correlate with a decrease in QoL. In a cross-sectional study of 68 adult patients with CD and 35 adult patients with UC showed that mild-to-moderate malnutrition was present in 17 patients.<sup>36</sup> The Subjective Global Assessment screening tool was used to identify malnutrition, and the RAND 36-item Health Survey was used to assess QoL. In another study, 78 inpatients with IBD were recruited to complete questionnaires with the IBD Questionnaire, Perceived Social Support Scale, Hospital Anxiety and Depression Scale, Perceived Stress Scale, Crohn's Disease Activity Index, and the Nutritional Risk Screening 2002.<sup>37</sup> Out of the 78 patients, 76 patients had anxiety, 71 patients had depression, and 46 patients were identified to be at risk for malnutrition. The presence of active disease was associated with the risk of malnutrition as well as anxiety, depression, and reduced QoL. Food avoidance also contributed to malnutrition and food-related anxiety.

## FOOD-RELATED QUALITY OF LIFE AND OTHER GASTROINTESTINAL DISORDERS

In brief, the following discussions will highlight FRQoL and its sociocultural influences in the realm of other GI disorders.

### *Celiac Disease*

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Celiac disease (CeD) is an immune dysregulation that results in damage to the lining of the small bowel because of gluten consumption.<sup>38</sup> Gluten is a storage grain protein found in wheat, barley, rye, and malt. In review of the results from the 2009 to 2012 National Health and Nutrition Examination Survey, non-Hispanic whites were more likely to have CeD compared with other races.<sup>39</sup> The gluten-free (GF) diet is the lifetime treatment of CeD.

There are varying impacts of the GF diet on HRQoL in adolescents and adults. In adolescents, the taste of GF products may not be as appealing and may result in not making substitutions for gluten, leading to restrictive eating.<sup>40</sup> Navigating the GF diet while dining out and traveling with friends is shown to be a burden. In adults, adherence to the GF diet along with symptom control has been shown to improve QoL<sup>41</sup>; however, high attentiveness to the diet with very strict adherence has also been shown to increase anxiety and reduce QoL.<sup>42</sup> Food insecurity with GF products is known because cost and access to GF products may vary within regions. In a study that compared cost and availability of GF products to gluten-containing products in the United States, it was shown that the cost of GF products was 183% more than the gluten-containing products.<sup>43</sup> Patients experiencing food insecurity had lower adherence to the GF diet and, overall, were shown to have reduced HRQoL. Other sociocultural influences on FRQoL are not known in CeD.

### *Gastroparesis*

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Gastroparesis is delayed gastric emptying of contents from the stomach into the small intestine without a mechanical obstruction present.<sup>44</sup> In review of data from the National Institutes of Health Gastroparesis Consortium, the prevalence of diabetic gastroparesis is greater in non-Hispanic blacks and Hispanics than non-Hispanic whites. With regard to symptoms, non-Hispanic blacks had more vomiting than Hispanic patients. Further studies are needed because there are less data on FRQoL as well as its sociocultural influences. These data include patients living with gastroparesis who report social isolation in conjunction with intolerance and changes with diet.<sup>45</sup> A study on evaluating stigma experiences in patients with gastroparesis showed that questions asked of why only small portions are eaten and comments for diet-related unsolicited advice contributed to psychological distress.<sup>46</sup>

### *Irritable Bowel Syndrome*

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IBS is a disorder of gut–brain interaction, which is associated with recurrent abdominal pain and alterations between diarrhea and constipation as well as mixed components of both as determined by the Rome IV criteria.<sup>47</sup> The prevalence of IBS based on Rome IV criteria was found to be similar among the United States, Canada, and the United Kingdom at 4.4% to 4.8%.<sup>48</sup> Food avoidance and restriction is known to reduce FRQoL in IBS,<sup>49</sup> as well as there is a reduced QoL and higher symptom severity with more self-reported food intolerances.<sup>50</sup> With a highlight, the 3-phase low-FODMAP diet has been shown to promote symptom reduction in IBS and, in turn, increase QoL.<sup>51,52</sup> Sociocultural influences on FRQoL are not known in IBS.

## PERSPECTIVE OF THE LIVED EXPERIENCE

As a patient who has had multiple colorectal surgeries to treat her CD, patient advocate and coauthor of this article, Tina Aswani-Omprakash, shares her lived experience with sociocultural aspects that contributed to the loss of her FRQoL. From being in recurrent active disease to frequent changes in medications to undergoing a colectomy, j-pouch, fistula repair, and stoma creation, Aswani-Omprakash has faced the highs and lows of the psychosocial impact and food-related anxiety in living with virulent IBD. This in addition to subsequent diagnoses of IBS, gastroparesis, and small intestinal bacterial overgrowth (SIBO), Aswani-Omprakash has faced significant challenges in managing her diet in the setting of having multiple diagnoses. This has led to many mental health challenges around food, which is something she has had to navigate to regain FRQoL.

As a practicing lacto-vegetarian, Aswani-Omprakash was often told to “at least eat eggs or fish for protein” without further consideration for her diet or for her religious beliefs within Hinduism. After undergoing the initial surgery, she was told to consume foods such as bread, applesauce, bananas, and rice, none of which really encompassed the cultural foods she was used to eating such as roti (Indian bread), vegetable curries, and dal (lentil). There was also minimal guidance on how to reintroduce fiber after having her colon removed, which left her navigating her food-related anxiety along with her food choices on her own.

Throughout the years, she thought she was not a part of her culture because of not being able to eat many of the spicy, fried, or sweet dishes that are enjoyed during many celebrations. During religious rituals, she was not able to eat prasad (food offering) to pay reverence. At weddings, she was not able to enjoy the mélange of foods and was often asked multiple questions around why she is not eating or enjoying herself at the weddings. Not being able to partake in religious or cultural events with friends and family has left her feeling like she stands out like a sore thumb and that she has offended those around her by not accepting their offerings for food. These experiences have taken away from her the ability to feel like she too can have the same richness of cultural experience as her friends and family.

In addition to the above challenges, she again developed obstructive and constipation-related symptoms in the setting of SIBO after having had so many surgeries. She desperately self-restricted carbohydrates that were deemed fermentable in hopes to reduce the symptoms. Her diet, already limited to begin with as a vegetarian, now has further limitations. She eventually underwent another surgery malnourished to remove multiple sites of bowel obstruction and scar tissue. There were significant concerns on what her recovery would entail after surgery.

Now a few months out of surgery, Aswani-Omprakash describes feeling scared about reintroducing carbohydrates. She is not only afraid of eating sandwiches that contain bread, she is also afraid of eating pastas and even legumes that may potentially ferment in her small bowel. Reintroducing these foods has been a challenge and every time she experienced symptoms, she is set back for several weeks emotionally and physically. She describes it as a crippling cycle to reintroduce foods, have symptoms, and then develop fears around those foods again, which was enough to self-restrict again.

Moreover, Aswani-Omprakash faced significant socioeconomic barriers to care that led to financial hardship. A day before her initial surgery, she received a telephone call from her Human Resources department informing her that she has been terminated from her job which led her to urgently apply for Consolidated Omnibus Budget Reconciliation Act (COBRA) health insurance and overall, care for herself financially during and after surgery. As a 24-year-old woman, she had to pay several hundred dollars

a month for health insurance along with copays, coinsurance, and deductibles. In addition, she was responsible to cover fees toward intravenous parenteral nutrition because she was not able to eat in sufficient amounts through diet just yet. Once she tapered off parenteral nutrition, she also paid for enteral nutrition formulas around the clock as she began to slowly reintroduce foods back into the diet. This was in addition to the household payments she helped her mother with and to cover the cost of the car trips, tolls, and parking garages she had to pay at clinic visits for specialized care twice a week on average. Aswani-Omprakash describes this experience as back-breaking, from trying to get through surgery physically and emotionally. She thought she could not afford to eat healthy in the setting of trying to meet the financial demands of her care.

Nevertheless, Aswani-Omprakash endured through the many challenges and has come out on the other side managing all of her chronic digestive ailments with the help of her multidisciplinary specialists and regaining FRQoL and, therefore, overall QoL with the guidance of her GI dietitian and her psychologist.

### **FUTURE DIRECTIONS**

Overall, there are limited studies here on how sociocultural influences affect FRQoL. In addition to diet acculturation, another consideration to factor in for FRQoL is that changes in food culture may arise with the use of therapeutic diets, which may affect the adherence to diets. As food insecurity is a social/environmental contributor to malnutrition, learning of its extent is needed to identify resources to improve access and adherence to diet to reduce malnutrition. Sociocultural considerations overall warrant additional studies and resources to evaluate influences on FRQoL, which include changes in food culture, process of diet acculturation, existence of food insecurity, presence of diet-related disparities, and level of diet quality.

It is imperative to learn of sociocultural influences as part of a clinical, nutrition, and psychosocial evaluation of a patient to aid in developing culturally competent interventions to optimize FRQoL, especially of various races and ethnicities. Perhaps, the most salient improvement of FRQoL involves a multidisciplinary team of physicians, nurses, dietitians, psychologists, and social workers to implement clinical guidelines and interventions in a way to best help the patient. A partnership between the patient and the various providers of the team must be in place to help bring discussions forward on how to balance disease management along with sociocultural influences on diet and FRQoL.

### **CLINICS CARE POINTS**

- Patients with IBD have reported food insecurity and minimal social support.
- Diet inadequacies have been correlated with reduced FRQoL.
- Further studies are indicated to identify the presence of sociocultural influences on FRQoL in IBD to also help determine culturally competent interventions, especially in racial and ethnic groups.

### **DISCLOSURE**

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