

## PRACTICE APPLICATIONS

## Case Study



# The Specific Carbohydrate Diet for Inflammatory Bowel Disease: A Case Series

**T**HE PATHOGENESIS OF INFLAMMATORY bowel disease (IBD) is thought to be multifactorial, involving a genetically susceptible individual being exposed to a yet-to-be identified environmental trigger or set of triggers. There is growing evidence that IBD may be a disease of Westernization associated with diets high in refined sugars; bread and cereals; proteins, especially dairy; and n-6 polyunsaturated fatty acids acquired from highly processed seed oils. However, the evidence is often low quality, conflicting, and inconclusive.<sup>1-5</sup>

The Specific Carbohydrate Diet (SCD) is a dietary program that claims to induce and maintain drug-free remission in patients with IBD. It was initially developed by gastroenterologist Sidney Haas in 1951 and later popularized by biochemist Elaine Gottschall in the book *Breaking the Vicious Cycle: Intestinal Health Through Diet*.<sup>6,7</sup> The diet allows carbohydrate foods consisting of monosaccharides only and excludes disaccharides and most polysaccharides (such as linear or branch-chained multiple sugars or starches). The diet is supplemented by homemade yogurt fermented for 24 hours to free it of lactose, a disaccharide not allowed in the SCD. Recommended cultures include *Lactobacillus bulgaricus*, *Lactobacillus acidophilus*, and *Streptococcus thermophilus*. The

SCD allows almost all fruits, vegetables containing more amylose (a linear-chain polysaccharide) than amylopectin (a branch-chained polysaccharide), nuts, nut-derived flours, dry-curd cottage cheese, meats, eggs, butters, and oils. It excludes sucrose, maltose, isomaltose, lactose, grain-derived flours and all true and pseudograins, potatoes, okra, corn, fluid milk, soy, cheeses containing high amounts of lactose, as well as most food additives and preservatives. The typical starting dieter begins eating foods that are thought to be well tolerated, including cooked, peeled, and seeded fruits and vegetables, and over time other foods are added slowly to partially liberalize the diet.

The SCD is not a low-carbohydrate diet, but rather a diet that is predominantly composed of monosaccharides, solid proteins, fats, a high ratio of amylose to amylopectin vegetables, fruits, and nuts. Gottschall<sup>7</sup> hypothesized that patients with IBD can only optimally absorb the monosaccharides glucose, galactose, and fructose due to a dysfunction of the host's disaccharidases that are necessary for digestion and absorption of disaccharides and high amylopectin foodstuffs. This dysfunction is posited to arise from excessive mucus production preventing the brush border intestinal enzymes from making contact with the disaccharidases and amylopectin causing maldigestion. Further, toxic substances produced by dysbiosis of the luminal microbiota (eg, the overgrowth of yeast and bacteria) in the small intestine may cause damage to intestinal cell membranes and destroy brush boarder enzymes.<sup>7</sup> A diet containing carbohydrate from primarily monosaccharide sources such as fructose (as in fruits and honey) and higher amylose:amylopectin vegetables, butter or oils, and solid proteins could optimally nourish a patient with

IBD and result in lower amounts of disaccharide sugars entering the colon, preventing and reversing a significantly altered and dysfunctional microbiota postulated to be present in the gastrointestinal tract of patients with IBD.<sup>7</sup>

Neither the characteristics of patients who are following the SCD nor the benefits of this diet have been well described in the medical literature. Herein, we report on the largest series of patients with IBD following the SCD to date and describe their clinical characteristics.

## PATIENT OVERVIEW

We collected survey data from patients with IBD following the SCD living within the continental United States. Subjects were recruited through advertisements posted on SCD message boards and websites as well as through our own gastroenterology clinics. Subjects mailed their medical records and filled out a structured survey of their medical history, a 3-day diet diary, and a validated disease activity index. The modified Harvey-Bradshaw Index was used for Crohn's disease (CD),<sup>8</sup> the St Mark's Index was used for ulcerative colitis (UC),<sup>9</sup> and both indexes were used for cases of indeterminate colitis (ID). Presence of gastrointestinal symptoms within 1 week of the data collection was assessed with the use of a structured survey called the Gastrointestinal Symptom Severity Checklist, which is designed similarly to validated Gastrointestinal Symptom Rating Scale but expanded to include additional symptoms that may not be captured by the Gastrointestinal Symptom Rating Scale.<sup>10</sup> In addition, on the Gastrointestinal Symptom Severity Checklist each subject is asked to rate one symptom at a time on a visual analog scale from 0 to 10,

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**Table 1.** Demographic characteristics of a cohort of 50 patients with inflammatory bowel disease in remission following the Specific Carbohydrate Diet

Case no.	Disease	Location	Age	Sex	Duration of disease (mo)	Duration of diet (mo)	Level of education	Forbidden food(s)	Medication(s)
1	UC <sup>a</sup>	Pancolitis	56	M <sup>b</sup>	288	76	College	None	LDN <sup>c</sup>
2	UC	Rectosigmoid	56	F <sup>d</sup>	384	216	College	None	None
3	UC	Pancolitis	41	F	36	9	College	None	Mesalamine (Asacol <sup>e</sup> ), LDN, azathioprine
4	UC	Rectosigmoid	35	F	108	82	College	None	LDN
5	UC	Rectosigmoid	38	F	204	40	College	None	Mesalamine suppositories
6	UC	Rectosigmoid	41	M	48	13	Graduate degree	None	Mesalamine (Lialda <sup>f</sup> ), mesalamine enema
7	UC	Rectosigmoid	32	F	132	7	College	None	Infliximab
8	UC	Proctitis	35	M	24	4	Graduate degree	None	Mesalamine (Lialda)
9	UC	Pancolitis	25	F	324	2	Graduate degree	None	Prednisone (1 mg), sulfasalazine (Azulfadine <sup>g</sup> ), mesalamine enema
10	CD <sup>h</sup>	Ileocolonic	29	M	324	19	Graduate degree	None	Mesalamine (Pentasa <sup>i</sup> ), infliximab
11	CD	Colonic	61	F	36	10	High school	None	Mesalamine
12	CD	Colonic	48	M	24	6	Graduate degree	None	None
13	CD	Ileocolonic	27	M	156	8	College	None	Adalimumab, LDN, budesonide
14	CD	Colonic	40	F	72	60	Graduate degree	Chocolate	None
15	CD	Upper GI+colonic	10	M	60	39	Middle school	Ice cream	None
16	CD	Upper GI+ileocolonic	11	F	24	8	Middle school	Rice	Mesalamine (Asacol)
17	CD	Ileocolonic	31	F	156	14	College	None	Prednisone (1.5 mg), infliximab, LDN
18	CD	Upper GI+ileocolonic	11	M	24	7	Middle school	None	None
19	CD	Upper GI+ileocolonic	9	M	84	66	Middle school	None	None
20	CD	Ileum	52	M	36	14	College	None	Mesalamine (Pentasa)
21	CD	Upper GI+ileum	49	M	384	5	College	None	None
22	CD	Ileocolonic	41	M	192	31	College	None	Balsalazide
23	CD	Upper GI+colonic	13	F	36	14	Middle school	Cream, canned vegetables, eucharist host	None
24	CD	Ileocolonic	44	M	348	72	College	Coffee	None
25	CD	Colonic	19	F	24	1	College	None	None

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**Table 1.** Demographic characteristics of a cohort of 50 patients with inflammatory bowel disease in remission following the Specific Carbohydrate Diet (*continued*)

Case no.	Disease	Location	Age	Sex	Duration of disease (mo)	Duration of diet (mo)	Level of education	Forbidden food(s)	Medication(s)
26	CD	Colonic	37	F	36	16	Graduate degree	None	None
27	CD	Ileum	65	M	420	132	Graduate degree	None	Mesalamine (Asacol), mesalamine enema, colestipol
28	CD	Ileocolonic	49	F	120	12	College	Espresso	6-MP <sup>k</sup>
29	CD	Colonic	44	M	300	2	College	None	None
30	CD	Colonic	30	F	36	14	College	Coconut water, chocolate	Mesalamine (Lialda)
31	CD	Ileocolonic	31	F	132	111	College	None	None
32	CD	Colonic	39	M	276	158	Graduate degree	Salad dressing	None
33	CD	Ileocolonic	58	F	384	24	Graduate degree	None	LDN
34	CD	Ileum	51	F	48	6	Graduate degree	None	None
35	CD	Colonic	43	F	24	9	College	None	None
36	CD	Colonic	29	F	36	17	College	Potatoes	None
37	CD	Upper GI+ileum	19	M	36	13	High school	Brown rice, corn	6-MP
38	CD	Upper GI+colonic	52	F	168	162	College	Matzah once a year	None
39	CD	Colonic	42	F	48	10	Graduate degree	None	Mesalamine (Asacol)
40	CD	Colonic	49	F	24	4	College	None	Mesalamine (Lialda)
41	CD	Colonic	59	F	84	12	College	Milk, candy, cookies	Mesalamine (Lialda)
42	CD	Ileocolonic	11	F	24	8	Middle school	None	Loperamide (Imodium)
43	CD	Ileocolonic	15	F	12	6	High school	None	Mesalamine (Asacol), 6-MP
44	CD	Gastric	12	M	36	22	Middle school	School lunches	None
45	CD	Ileocolonic	29	M	60	60	Graduate school	None	LDN, adalimumab
46	ID <sup>l</sup>	Sigmoid to distal transverse, rectal sparing	31	F	84	6	Graduate degree	None	Mesalamine (Asacol)
47	ID	Right colon	17	M	60	8	High school	Corn tortillas, potatoes	Methotrexate
48	ID	Rectosigmoid	56	F	48	16	College	None	None

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**Table 1.** Demographic characteristics of a cohort of 50 patients with inflammatory bowel disease in remission following the Specific Carbohydrate Diet (*continued*)

Case no.	Disease	Location	Age	Sex	Duration of disease (mo)	Duration of diet (mo)	Level of education	Forbidden food(s)	Medication(s)
49	ID	Pancolitis, sparing rectum	39	M	240	72	Graduate degree	Spelt bread, raw milk, baked goods	None
50	ID	Right colon, rectosigmoid	46	M	108	48	College	Pizza	Hydrocortisone enema

<sup>a</sup>UC=ulcerative colitis.<sup>b</sup>M=male.<sup>c</sup>LDN=low-dose naltrexone.<sup>d</sup>F=female.<sup>e</sup>Asacol (Warner Chilcott Company, LLC).<sup>f</sup>Lialda (Shire US, Inc).<sup>g</sup>Azulfadine (Pfizer, Inc).<sup>h</sup>CD=Crohn's disease.<sup>i</sup>Pentasa (Shire US, Inc).<sup>j</sup>GI=gastrointestinal.<sup>k</sup>6-MP=6-mercaptopurine.<sup>l</sup>ID=indeterminate colitis.

with higher scores corresponding to increasing severity and frequency of the symptom. The subject's quality of life was assessed by a validated instrument, the Short Quality of Life in Inflammatory Bowel Disease Questionnaire (SIBDQ).<sup>11</sup> Subjects also rated their self-adherence to the SCD and the effectiveness of the SCD on a visual analog scale of 0% to 100%.

Subjects were included in the study if they had documented IBD by a physician within the United States and reported to follow the SCD. All diagnoses of IBD were confirmed by review of endoscopy, radiology, and pathology reports by a board-certified gastroenterologist who specializes in IBD at Rush University. Remission was defined as a Harvey-Bradshaw Index <5 for CD and St Mark's Index <4 for UC. Both surveys needed to reflect remission for ID.

### Ethical Considerations

The Rush University Medical Center Institutional Review Board approved the study protocol and all participants provided written informed consent (and child assent, if appropriate).

### INTERVENTION RESULTS

We obtained data on 50 cases in remission: 36 subjects had CD, 9 subjects had UC, and 5 subjects had ID. The subject demographic characteristics

and disease locations are given in Table 1. The mean age was 36 years (range=10 to 66 years). Twenty-nine subjects (58%) were female. Of patients with CD, the most highly represented subtype was colonic disease in 16 patients (three of whom also had upper GI involvement) and ileocolonic disease in 14 patients (three of whom also had upper GI involvement). Of the patients with UC, six had left-sided disease and two had pancolitis. All subjects were in remission: the mean Harvey Bradshaw Index was 0.9 (range=0 to 4) and the mean St Mark's Index was 1.4 (range=0 to 3).

The mean GSSC score was 27.1 for CD, 25.9 for UC, and 13.6 for ID (range=0 to 144), reflecting mild gastrointestinal symptoms. The individual symptom scores are shown in Table 2.

Patients following the SCD in remission had a high quality of life with a mean SIBDQ score of 60.9 (range=35 to 70). The results for the subscales of SIBDQ are given in Table 3.

The breakdown of medication use among the subjects with CD and UC are given in Table 1. In the CD group, eight subjects were taking immunosuppressive medications and only one patient was not steroid-free and was taking prednisone at a dose of 1.5 mg daily. Nineteen subjects with CD were not taking any medications for their IBD.

Past medication use in this group before starting the diet included mesalamine-based drugs in 15 subjects, prednisone in 12 subjects, budesonide in two subjects, 6-MP in four subjects, infliximab in one subject, certolizumab in one subject, ciprofloxacin in four subjects, and metronidazole in six subjects. In the UC group, three patients were taking immunosuppressive agents and only one patient was not steroid-free and was taking prednisone at a dose of 1 mg daily. One subject with UC was not taking any medications. Prior use of medications in this subject included prednisone, 5-aminosalicylates, and 6-MP. In the ID group, one subject was taking an immunosuppressive agent. Two subjects with ID were taking no medications. Prior use of medications in this group included prednisone and mesalamine drugs in both subjects and infliximab and ciprofloxacin in one subject. Therefore, out of 22 patients who were taking no medications at all, 16 had discontinued all steroids (14 were taking prednisone and two were taking budesonide), three had discontinued TNF inhibitors, and five had discontinued 6-MP and had remained in remission.

The mean time the SCD was followed was 35.4 months (range=1 to 216 months). Forty-four subjects (88%) reported eating the SCD yogurt, 33 of

**Table 2.** Gastrointestinal Symptom Severity Checklist (GSSC) results for cohort of 50 patients with inflammatory bowel disease in remission following use of the Specific Carbohydrate Diet

GSSC item	Crohn's Disease (n=36)		Ulcerative Colitis (n=9)		Indeterminate Colitis (n=5)	
	% >0	Mean	% >0	Mean	% >0	Mean
Upper abdominal pain or discomfort	27.8	0.6	33.3	0.7	20.0	0.2
Lower abdominal pain or discomfort	44.4	0.8	55.6	1.4	20.0	0.2
Upper abdominal cramping	16.7	0.4	11.1	0.1	0	0
Lower abdominal cramping	22.2	0.4	22.2	0.6	0	0
Pain associated with eating	11.1	0.4	22.2	0.4	0	0
Bloating	30.6	1.3	33.3	1.2	40.0	0.8
Belching	33.3	0.7	33.3	0.6	20.0	0.4
Passing gas	66.7	1.8	77.8	2.2	40.0	0.6
Excessive gas overall	38.9	1.2	66.7	1.2	20.0	0.2
Heartburn	16.7	0.6	33.3	0.7	20.0	1.6
Indigestion	13.9	0.3	33.3	0.7	0	0
Nausea	13.9	0.6	22.2	0.6	20.0	0.4
Nausea associated with eating	13.9	0.5	11.1	0.3	20.0	0.4
Frequent bowel movements	13.9	0.9	33.3	0.6	20.0	0.2
Vomiting	13.9	0.4	0	0	0	0
Alternating bowel movements between constipation and diarrhea	22.2	0.4	33.3	0.8	20.0	0.2
Constipation >70% of the time	22.2	0.5	11.1	0.3	0	0
Diarrhea >70% of the time	33.3	1.0	11.1	0.1	0	0
Irregular bowel habits	30.6	0.8	33.3	0.4	20.0	0.2
Infrequent bowel movements	27.8	0.5	33.3	0.7	0	0
Hard stools	36.1	1.0	33.3	0.7	20.0	0.4
Watery stools	47.2	1.6	44.4	0.9	20.0	0.6
Soft stools	41.7	1.6	66.7	3.6	60.0	1.4
Passage of mucous in the stool	19.4	0.5	33.3	1.3	20.0	0.2
Passage of blood in the stool (without presence of hemorrhoids)	27.8	0.8	33.3	0.8	20.0	0.2
Straining with bowel movements	38.9	0.9	11.1	0.4	0	0
Fecal urgency	41.7	1.4	66.7	1.1	40.0	1.0
Bowel incontinence	13.9	0.5	0	0	0	0
Sensation of incomplete emptying of bowels	38.9	0.7	55.6	0.8	20.0	0.2
Loss of appetite	11.1	0.5	22.2	0.2	0	0
Weight loss	27.8	0.9	55.6	1.8	40.0	1
Decreased food intake because of symptoms	13.9	0.6	11.1	0.1	0	0
Difficulty swallowing	2.8	0	0	0	0	0
Pain with swallowing	0	0	0	0	0	0
Food coming up to mouth	2.8	0.1	0	0	0	0
Acid taste in mouth	5.6	0.1	0	0	20.0	1.6
Intolerance to multiple foods	38.9	1.8	33.3	0.7	20.0	1.6
Overall	86.1	27.1	88.9	25.9	80.0	13.6

**Table 3.** Short Quality of Life in Inflammatory Bowel Disease Questionnaire (SIBDQ) of a cohort of 50 patients in remission following use of the Specific Carbohydrate Diet

Patient's condition	SIBDQ Subscale Scores (mean±standard deviation)				
	Bowel	Systemic	Emotional	Social	Total
Overall (n=50)	18.9±2.4	11.7±2.2	16.7±3.3	13.5±1.1	60.9±6.5
Crohn's disease (n=36)	18.8±2.6	11.9±2.1	16.6±3.5	13.5±1.3	60.9±6.9
Ulcerative colitis (n=9)	18.4±2.1	11.3±2.3	16.7±2.7	13.4±0.9	59.9±5.7
Indeterminate colitis (n=5)	20.4±0.9	11.6±2.9	17.2±3.4	14.0±0.0	63.2±4.3

whom (67%) ate it daily. Twenty-six subjects (52%) reported using a supplementary probiotic. The most common probiotics used were *Lactobacillus* and *Acidophilus* species (13 CD patients and four UC patients) and *Saccharomyces boulardii* preparations (4 CD patients and one UC patient).

Patients' self-rating of compliance with the SCD diet on a visual analog scale of 0% to 100% had a mean adherence rating of 95.2% (range=71% to 100%). The Figure shows an example of a 3-day diet diary of one of the subjects in the study that is an accurate representation of the foods allowed on the SCD. Although the diet requires strict adherence, there were still 16

subjects (32.1%) (12 CD patients and four ID patients) who reported occasional ability to eat some "forbidden" foods (Table 1). Of these 16 subjects, 14 had CD and two had ID. All subjects were eating SCD yogurt and had been following the SCD diet for at least 8 months. Seven (43.7%) of these 16 patients who were eating "forbidden" foods were also taking some type of maintenance medication (Table 1).

Table 4 shows the reasons that patients started the SCD. Forty-one patients (82%) reported that one of the reasons they started the diet was fear of long-term consequences of medications. Other common reasons included the belief that the SCD was more

effective than medications (64%), medications were not effective (64%), adverse reaction from a prior medication (56%), and recommendations from Internet forums (44%).

Mean time for food preparation per week was 10.8 hours (range=0 to 32 hours). Twenty-four (58.5%) of 41 adult subjects were able to hold full-time jobs while implementing the diet. Mean time to see some improvement when following the SCD was 29.2 days (range=1 to 180 days). Thirty-three subjects (66%) noted complete symptom resolution, which did not occur until a mean of 9.9 months (range=1 to 60 months) after starting the SCD. Patients' self-report of the effectiveness of the SCD was obtained via visual analog scales: SCD was rated as a mean of 91.3% effective in controlling acute flare symptoms (range=30% to 100%) and a mean of 92.1% effective at maintaining remission (range=53% to 100%). Subjects reported a mean of 40% difficulty rating in following the diet (range=0% to 100%).

### DISCUSSION AND LESSONS LEARNED

This is the first clinical description of a large series of patients with IBD following the SCD. Our survey results suggest that SCD can potentially be an effective tool in the management of some patients with IBD and specifically in patients with colonic and ileocolonic CD who made up the majority of our study group. A highly educated group of patients follow the SCD; all but one of the adults in our study had a college or graduate degree. Our results also suggest that in some patients with moderate to severe disease who follow this diet, discontinuation of immunosuppressive agents has been feasible.

One of the strengths of our study is the verification of the diagnosis of IBD in all of the patients with medical record reviews by an experienced gastroenterologist who specializes in IBD. Our limitations include the choice of our subjects, all of whom were in remission, biasing our findings toward including patients with IBD who have benefited from SCD and were following it for months. Nevertheless, we now show that at least a subgroup of patients with IBD may notably improve as a result of following the SCD and/or dietary interventions in general. Our findings enhance those of prior limited

Day 1	
Breakfast	2 eggs, yogurt with farmer's cheese, honey
Lunch	Cube steak, apples, green beans, carrots
Dinner	Steak, carrots, green beans
Snacks	Grape juice, gelatin, peanut butter brownies, apples
Day 2	
Breakfast	2 eggs, yogurt with farmer's cheese, honey
Lunch	Steak, apples, asparagus
Dinner	Turkey burger (no bun), apples, carrots, boiled shrimp
Snacks	Peanut butter brownies, grape juice
Day 3	
Breakfast	3 eggs, yogurt, honey
Lunch	Chicken thighs, asparagus, baked apples, honey
Dinner	Pork with pineapple, carrots, asparagus, peaches
Snacks	Peanut butter brownies, grape juice

**Figure.** Actual 3-day food diary for one patient following the Specific Carbohydrate Diet demonstrating a representative menu.

**Table 4.** Reasons reported by cohort of 50 patients with inflammatory bowel disease in remission for choosing to implement the Specific Carbohydrate Diet (SCD)

Reason	Cases (n)	%
Fear of long-term consequences of medications	41	82
Efficacy of SCD compared with medications	32	64
Medications not effective	32	64
Adverse reactions to medications	28	56
Recommendation from Internet forum	22	44
Recommendation from family/friends	15	30
<i>Breaking the Vicious Cycle</i> book <sup>7</sup>	4	8
Cost of medications	1	2
Seeking alternative treatment to medications	1	2
Fear of need for surgery	2	4
Fear of colon cancer	1	2

case reports of dietary therapy with SCD and other dietary interventions.<sup>12-16</sup> Other, more long-term diet interventions that are not SCD have shown promise in a very limited number of subjects.<sup>17,18</sup>

Further evidence suggesting diet can be an effective treatment for some patients with IBD stems from the fact that diet has the potential to change the intestinal luminal environment, specifically the intestinal microbiome. Our prior preliminary findings<sup>19,20</sup> hint at a change in the microbiome of patients with IBD who follow the SCD. If following the SCD changes the microbiome significantly and/or reverses some of the dysbiosis reported in patients with IBD, this may be a low-cost intervention to induce and maintain remission with little or no known adverse reactions. As such, further interventional studies of SCD and diet therapies in general for IBD are urgently needed.

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**DISCLOSURES**

**STATEMENT OF POTENTIAL CONFLICT OF INTEREST**

No potential conflict of interest was reported by the authors.

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