


Patients Perceive Clinical Benefit with the Specific Carbohydrate Diet for Inflammatory Bowel Disease

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Abstract

Background Recent studies suggest that dietary therapy may be effective for patients with inflammatory bowel disease (IBD), but limited published data exist on the usage and efficacy of dietary therapy.

Aim To evaluate the perspective of IBD patients using the specific carbohydrate diet (SCD).

Methods An anonymous online survey was conducted using REDCap, a Web-based survey tool. Survey links were sent to known Web sites as well as support groups in an attempt to characterize patient utilization of the SCD and perception of efficacy of the SCD.

Results There were 417 respondents of the online survey on the SCD with IBD. Mean age for individuals on the SCD was 34.9 ± 16.4 years. Seventy percent were female. Forty-seven percent had Crohn's disease, 43 % had ulcerative colitis, and 10 % had indeterminate colitis. Individuals perceived clinical improvement on the SCD. Four percent reported clinical remission prior to the SCD, while 33 % reported remission at 2 months after initiation of the SCD, and 42 % at both 6 and 12 months. For those reporting clinical remission, 13 % reported time to achieve

remission of less than 2 weeks, 17 % reported 2 weeks to a month, 36 % reported 1–3 months, and 34 % reported greater than 3 months. For individuals who reported reaching remission, 47 % of individuals reported associated improvement in abnormal laboratory values.

Conclusions The SCD is utilized by many patients as a primary and adjunct therapy for IBD. Most patients perceive clinical benefit to use of the SCD.

Keywords Crohn's disease · Ulcerative colitis · Inflammatory bowel disease · Specific carbohydrate diet · Diet · Nutrition

Introduction

Inflammatory bowel disease (IBD) is an immune dysregulation triggered by environmental factors and the fecal microbiome in a genetically susceptible individual. The primary therapies for IBD focus on suppressing the immune response in order to eliminate inflammation, but dietary therapy with exclusive enteral nutrition (EEN) has also been shown to be an effective therapeutic option [1]. With further evidence mounting in regard to the role of the fecal microbiome in IBD, research is now focusing on alternative therapies, including diet, which could modulate environmental exposures and the fecal microbiome and thus decrease the inflammatory response.

Aside from EEN, diet as a primary or adjunct therapy for IBD is not a standard approach to Crohn's disease or ulcerative colitis (UC) treatment. Despite this, alternative and complementary therapies which include diets are used frequently by patients with IBD [2]. Many diets have anecdotally been reported to be efficacious without rigorous scientific evaluation [3]. One of the more commonly

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used dietary therapies trialed is the specific carbohydrate diet (SCD). This diet was developed by Dr. Sydney Haas, a pediatrician, in the 1930s to treat patients with Celiac disease [4]. It was popularized in the late twentieth century by Elaine Gottschall whose daughter was successfully treated by Dr. Haas with SCD for her UC [5]. This diet excludes all grains, sugars except for honey, processed foods, and milk. The SCD purports decreased intestinal inflammation by restoring the balance of bacteria within the bowels and resolving the associated dysbiosis found in IBD.

Currently, a number of small studies evaluating the SCD for IBD therapy have shown clinical improvement and decline in objective markers in inflammation [6–9]. These studies evaluate therapeutic efficacy but lack assessment of patient perception of efficacy and tolerability of the SCD. To better understand patient perspective on the SCD, we undertook an online survey to evaluate attitudes and clinical practice of patients with IBD on the SCD.

Methods

We developed an online anonymous survey for patients with CD or UC who had been on SCD as dietary therapy. The SCD survey remained available for patient response from December 2014 to June 2015. The protocol was approved by the Seattle Children's Hospital Institutional Review Board (IRB study #15404). The survey contained 45 questions covering five main areas regarding usage of the SCD: patient demographics, reasons for initiation of SCD, maintenance of the SCD, disease complications before/after SCD, and healthcare management/follow-ups.

Demographic questions included age and sex. Clinical questions were structured to understand disease diagnosis, extent, and duration. Questions regarding initiation of the SCD focused on reasons for beginning the SCD and concomitant therapies at initiation of the SCD. Questions revolving around a SCD maintenance/course focused on changes in symptoms on the SCD, dietary adherence of the SCD, and changes in medication while on the SCD. Questions on healthcare management and follow-up focused on the interactions between patient and healthcare providers including gastroenterologist, dietitian, naturopath, and others healthcare providers. Finally, questions regarding disease complications delved into problems that occurred secondary to disease activity before and after initiating the SCD as well as difficulties and complications with the SCD itself. The survey link was sent to multiple Web sites for publication including breakingtheviciouscycle.info, scdlifestyle.com, scdrecipe.com, comfybelly.com, and patient support groups involved with the SCD including SCD support groups on Yahoo and Facebook.

Participants were asked to complete the survey only if they or a family member were on the SCD and had either CD or UC.

Calculation

The survey was administered and data was captured using REDCap [10]. Descriptive analysis of the data was performed using Stata 12.1 (Statacorp, College Station, TX, USA). All demographic and clinical variables were summarized using frequencies and percentages for categorical variables and mean, standard deviation, median, range, and interquartile range (IQR) for continuous variables, as appropriate. Survey responses were included in analysis if respondents completed the entire survey and clicked the submit button at the survey conclusion. To prevent confounding from repeated entries, partially completed surveys were not included in final analysis.

Results

In total, 578 individuals responded to the survey of which 417 subjects went through the entire survey, answered all question, and submitted their responses. Mean age for individuals on the SCD was 34.9 ± 16.4 years (range 1.5–70 years). Twenty-three percent of individuals were less than 19 years of age. Thirty percent of individuals were male and 70 % female. Forty-seven percent of individuals had CD, while 43 % had UC and 10 % had indeterminate colitis. For patients with Crohn's disease, 51 % reported large bowel disease, 16 % reported small bowel disease, and 22 % indicated both small and large bowel involvement. (Table 1) Initial source of knowledge for the SCD came primarily from the internet (59 %), from a family or friend (29 %), or from a healthcare provider (17 %). The mean duration on the SCD was 31.6 ± 54.9 months with the range of 0.25–780 months.

The reason for individuals starting the SCD was for avoidance of medication (49 %), incomplete improvement with medication (28 %), no improvement with medication (9 %), and/or side effects or allergies to medication (19 %). Forty-three percent of individuals on dietary therapy were on the strict SCD (unmodified), while 57 % of individuals made changes to their SCD food intake after initiating the diet. Deviation from an unmodified/strict SCD were guided by healthcare practitioner recommendation (12 %), based on online forum or Web site recommendation (13 %), because of missing a favorite food (23 %), because of food allergy/sensitivity (19 %), because of a medical intervention (4 %) or because of laboratory value abnormalities (3 %).

Table 1 Patient demographics

Patient characteristics	N (%)
Age group of SCD participants [<i>n</i> (%)]	
<10 years	24 (6)
10–19	70 (17)
20–29	52 (12)
30–39	95 (23)
40–49	91 (22)
50–59	48 (12)
60–69	25 (6)
≥70	3 (1)
Gender (% female)	70
Age at diagnosis of IBD [<i>n</i> (%)]	
0–10 years	55 (14)
10–17 years	75 (18)
17–40 years	181 (44)
≥40 years	96 (24)
IBD diagnosis [<i>n</i> (%)]	
Crohn's disease	188 (47)
Ulcerative colitis	174 (43)
Indeterminate colitis	38 (10)
For individuals with Crohn's disease location of disease at diagnosis [<i>n</i> (%)]	
Small bowel	66 (16)
Large bowel	210 (51)
Both small and large bowel	90 (22)
Unknown	42 (10)
IBD complications [<i>n</i> (%)]	
Bowel obstruction	33 (8)
Bowel resection	35 (8)
Drainage of abscess/infection	28 (7)
Fistula	46 (11)
C. difficile infection	32 (8)
Structure	36 (9)
Unknown	11 (3)
None of the above	283 (68)
Timing of IBD complications relative to starting SCD [<i>n</i> (%)]	
Before	101 (89)
After	7 (6)
Unknown	6 (5)
History of prior hospitalization for IBD [<i>n</i> (%)]	
No	241 (59)
Yes	168 (41)
If hospitalized, timing relative to start SCD	
Before	140 (83)
After	11 (7)

Forty-four percent of individuals on the SCD diet were not taking concomitant medication, while 56 % took medication in addition to the SCD. Medications taken for IBD included aminosalicylate (31 %), immune modulators (11 %), biologic or corticosteroids (17 %), antibiotics

(2 %), nutraceuticals/probiotics (9 %), and vitamins (35 %).

Overall, symptom decreased over time. Prior to starting the SCD 80 % of respondents had abdominal pain. After 2, 6, and 12 months, the individuals reporting abdominal pain

decreased to 24, 11, and 7 % respectively. Prior to starting the SCD, limitations in activities were reported by 65 % of respondents. After 2, 6, and 12 months, this decreased to 15, 7, and 4 % respectively. Prior to starting the SCD, diarrhea was reported by 81 % of individuals. After 2, 6, and 12 months, this decreased to 31, 18, and 10 %, respectively. Prior to starting the SCD, blood in the stool was reported by 67 % of individuals. After 2, 6, and 12 months, this decreased 19, 10, and 5 %, respectively. Prior to starting the SCD, weight loss was reported by 58 % of individuals. After 2, 6, and 12 months, this decreased 18, 9, and 4 %, respectively (Fig. 1).

There is a significant shift toward clinical improvement for majority of patients with 4 % perceiving they were in clinical remission prior to the SCD, 33 % perceiving remission at 2 months, and 42 % perceiving remission at 6 and 12 months (Fig. 2). For those who perceived that they were able to achieve clinical remission, the time it took to get into remission varied. Thirteen percent indicated remission within less than 2 weeks, 17 % reported remission by 2 weeks to a month, 36 % reported remission within 1 month to 3 months, and 34 % indicated taking greater than 3 months to achieve remission. For those individuals who reported remission, 47 % of individuals reported that this was associated with improvement in abnormal laboratory values, while 7 % reported no improvement in laboratory values, and 46 % were unsure. Age at time of survey completion, age at diagnosis, gender, IBD diagnosis, and location of disease were evaluated for association with achievement of remission status, and none of these characteristics demonstrated an association ($p > 0.26$ for all). When medications were evaluated, participants not on mesalamines, immunomodulators, and biologicals, respectively, were more likely to report remission on the SCD ($p < 0.009$ for all). Additional analysis to evaluate participants requiring immunosuppressive medications versus no

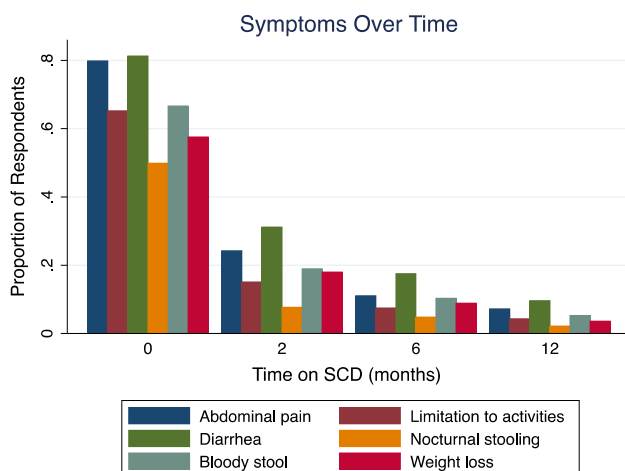


Fig. 1 Patient-reported symptoms over time once initiating the specific carbohydrate diet

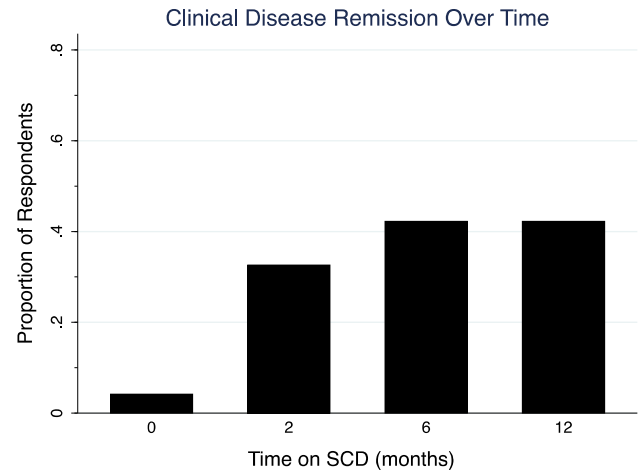


Fig. 2 Patient-reported remission over time once initiating the specific carbohydrate diet

immunosuppressive medications demonstrated that a significantly greater portion of subjects requiring no immunosuppression achieved remission (60.7 vs. 35.6 %; $p < 0.001$). Subjects who were hospitalized for their IBD versus not ever hospitalized had similar rates of reported remission on the SCD ($p = 0.87$).

Ninety-six percent of respondents continue on the SCD, while 4 % discontinued the SCD ($n = 18$). Of the 18 respondents who discontinued the SCD, 10 subjects reported achieving clinical remission of disease. Individuals who discontinued the SCD varied in terms of time on the SCD: Two followed the diet for less than 6 months, five adhered for 6–12 months, and 10 greater than 12 months. Of those stopping the SCD, 17 % felt that it was ineffective, 11 % had too much weight loss, 39 % felt it was too difficult to maintain, and 11 % felt it was too expensive.

Discussion

Dietary interventions including the SCD have been shown efficacious in small studies for both UC and Crohn's disease; however, the mechanism remains unclear [6–9]. Hypothesized mechanisms by which diet can effect GI tract inflammation include the mechanical properties of food, delivery of essential nutrients, impact on composition and function of the gut microbiota, alterations in bile acid secretion, and reduced exposure to deleterious compounds [11]. With this in mind and further larger-scaled dietary studies underway, we sought to evaluate the patient perspectives on dietary management with the specific carbohydrate diet for IBD.

Although not all patients in this study felt the SCD was effective, the majority of respondents felt that the diet did have a positive effect on their disease. Symptoms

diminished progressively with most of the improvement seen by 6 months. Over a third of patients felt the diet helped them go into clinical remission. This is true despite the majority of patients not maintaining a strict SCD as defined by Elaine Gottschall in “Breaking the Viscous Cycle” [5]. The survey results are similar to what we found in our retrospective study of SCD within our IBD center at Seattle Children’s Hospital [8].

This study demonstrated significant heterogeneity in the population using dietary treatment in IBD, with variability in disease phenotype, patient age, reasons for using diet, and concomitant medication exposures. Although age at time of survey completion, age at diagnosis, gender, IBD diagnosis, and location of disease did not demonstrate an association with disease remission, lack of concomitant medication including mesalamines, immunomodulators, and biologicals was more likely to report remission on the SCD. It is unclear why this association exists, but therapy with immunosuppressive medications may imply greater disease severity. Participants with a history of hospitalization, though, did not have different rates of reported remission. Adherence and interpretation of the SCD was highly variable with the reported addition of numerous new foods to the strict SCD. The variations in practice of the SCD introduce challenges for both patients and providers in evaluating the true efficacy of the diet. Based upon our personal experience, successful addition of foods to the SCD is possible, but requires further systematic evaluation.

With clinical studies showing a positive impact of the SCD on clinical symptoms and laboratory values [6–9], animal studies linking diet to the development of IBD in genetically predisposed animals [12–14], broad patient interest in diet as therapy, and 49 % beginning the diet because of the perception of risk from medications, integration of diet into the treatment paradigm of IBD is likely to evolve over the coming years. With this in mind, understanding the perspective of the patients will be an important element in effectively incorporating diet into conventional IBD therapy.

Although the results of the study suggests an overall benefit for patients on the SCD with the majority of patients going into clinical remission, there are limitations to this study. Our online questionnaire has not been validated as a tool to assess inflammatory bowel disease. With that caveat, the internet has been shown to be reliable in assessing accurately the health status of patients with inflammatory bowel disease [15]. Also given the anonymous nature of the study we are limited in our ability to verify the underlying diagnosis and clinical disease status of each patient. We were also unable to verify compliance with the diet in individuals. In addition this survey evaluates perceived benefit versus objective evidence of clinical remission. Though patients may feel clinically improved, it is quite possible that they still have ongoing inflammation.

Also, the majority of internet sites that the survey was sent to were SCD-specific interest sites, therefore introducing likely response bias. With this being said, the overall results of this anonymous survey shed further light on the use and perception of dietary therapy in IBD, and these findings are similar to our clinical experience in the IBD center. Dietary therapy is promising, but further study is required to better define the role of diet in inflammatory bowel disease. In addition, as further studies on the effect of dietary therapy in IBD are carried out, special attention is needed to focus on the unique challenges that occur with dietary therapy. While medication requires relatively little in the way of lifestyle change for an individual, dietary therapy requires significant changes in an individual’s daily life. This means for the SCD to be effective, medical community will need to develop patient support systems including routine integration of dietician into patient care.

Author contributions DS developed the concept of the study, while DS, GW, SC, CD, JK, KM, MS, and DL all contributed to design of the study, generation, collection, analysis, and interpretation of data as well as draft the manuscript and had approval of the final version of the manuscript.

Compliance with ethical standards

Conflict of interest None of the authors have a conflict of interest in regards to this article and have adhered to strict ethical standards.

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