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Dietary Fiber Information for Individuals with Crohn Disease: Reports of Gastrointestinal Effects

Carol S. Brotherton, MSN, RN and

University of Virginia, Center for the Study of Complementary and Alternative Therapies, Doctoral Candidate, P.O. Box 800782, Charlottesville, Virginia 22908-0782, 1-703-282-1656 (telephone), 1-434-243-9938 (FAX)

Ann Gill Taylor, EdD, MS, RN, FAAN

University of Virginia, Center Director, Center for the Study of Complementary and Alternative Therapies, P.O. Box 800782, Charlottesville, Virginia 22908-0782, 1-434-924-0113 (telephone), 1-434-243-9938 (FAX)

Carol S. Brotherton: csb8b@virginia.edu; Ann Gill Taylor: agt@virginia.edu

Abstract

The experiences of individuals with Crohn disease before and after receiving dietary fiber information have not been described in the literature. This article offers findings from a study that used four semi-structured audio recorded interviews during a 4-week time period for the purpose of exploring the experiences of 11 individuals before and after receiving dietary fiber information from a healthcare professional. The first and second interviews occurred immediately before and after the presentation of information. Follow-up interviews occurred at 2-week intervals. Thematic analysis of the baseline interviews revealed two themes: (a) accepting a redefined (lower expectations) definition of normal quality of life, and (b) continuing to look for answers. Three themes emerged from the follow-up interviews at week 4: (a) re-evaluating old diet-related concepts, (b) enjoying a healthier lifestyle at a self-set pace, and (c) enjoying positive physical effects of wheat bran consumption. This paper examines the third post-intervention theme, "enjoying physical effects of wheat bran consumption." The relevance of this research is that nurses equipped with dietary fiber information may be better able to help some individuals with Crohn disease to explore the potential benefits of a well-rounded nutritious pattern of eating that includes wheat bran cereal.

Crohn disease (CD) is a troubling inflammatory bowel disease (IBD) for those who have this chronic condition as well as for the healthcare providers treating them. Although a constellation of intestinal and extra-intestinal symptoms characterize the disorder, exacerbations of diarrhea, abdominal pain, and intestinal bleeding often predominate the clinical presentation. For many individuals, symptoms continue to recur despite availability and use of pharmacological and surgical intervention (Lichtenstein, Hanauer, & Sandborn, 2009). The continuing challenge presented by CD is evident in responses to a survey at the Cleveland Clinic in 2007 revealing that 68% of respondents with CD found their work to be affected by the symptoms of their disease and 25% found it necessary to change jobs as a result of these symptoms (Zutshi, Hull, & Hammel, 2007).

Researchers have questioned the relationship between dietary fiber and CD etiology and symptom expression for decades. By the 1980s, mounting evidence incriminated refined carbohydrates, especially white flour and white sugar, as epidemiologists considered the rising incidence of CD and other gastrointestinal diseases in Western countries (Burkitt, 1969, 1984; Cleave, 1975; Trowell, 1976).

In 1984, Burkitt suggested that a reduction in cereal fibers such as wheat bran in the refined Western diet was the predominant dietary change relevant to the increase in chronic intestinal disorders in North America and Western Europe (Burkitt, 1984). However, two 1980s clinical research studies failed to show a difference in CD-related outcomes for a group of individuals assigned to a low fiber diet group compared to a high fiber diet group (Levenstein, Prantera, Luzi, & D'ubaldi, 1985; Ritchie, Wadsworth, Lennard-Jones, & Rogers, 1987). Conclusions drawn from the 1980s fiber studies may be questioned in light of 21st century science. More recent Crohn disease and dietary fiber literature reveals mixed and inconclusive findings regarding the relationship between dietary fiber intake and CD etiology and symptoms (Chapman-Kiddell, Davies, Gillen, & Radford-Smith, 2010).

Recently, knowledge of the gut microbiota has exploded and offers a platform for relevant CD research (Clemente, Ursell, Parfrey, & Knight, 2012). Dietary fiber is a determinant of microbial composition and has therefore gained the attention of CD researchers interested in promoting beneficial gut bacteria (Macfarlane & Macfarlane, 2011; Macfarlane & McBain, 1999; Yamamoto, Nakahigashi, & Saniabadi, 2009). Although fractionated fiber extracts as food additives are currently of particular interest to some researchers (Benjamin et al., 2011; Casellas et al., 2007; Lindsay et al., 2006; Ramirez-Farias et al., 2009), testing of a high fiber diet featuring reintroduction of whole wheat bran into the low fiber Westernized diet (for those not gluten sensitive) is lacking in the literature. In contrast to fractionated fiber extracts, wheat bran cereal is a food that consists of more complete fiber. Wheat bran is a type of fiber that was automatically included in the human diet before the industrialization of foods resulted in systematic removal of important elements of whole grains (Hill, 1976).

The purpose of this current study was to explore with patients their experiences of living with CD, especially regarding food choices before and after receiving relevant information about dietary fiber and its effects in the gastrointestinal tract. Gaining insight into participants' levels of interest in receiving dietary fiber information, their ability to understand and use such information, and their feelings about the dietary changes they chose to implement may constitute a first step toward unraveling the complex task of choosing foods in the context of CD. Our goal is to guide future research that will improve health-related quality of life for those with CD based on patients' experiences voiced in this study and in accordance with the observed need for more patient-centered outcomes research (Patient-Centered Outcomes Research Institute [PCORI], 2012).

Methods

The researchers chose a qualitative method informed by phenomenology as the best approach for providing a comprehensive analysis of the phenomenon of interest. Qualitative approaches are especially useful when exploring new areas, such as the existing gap in our understanding of fiber-related food choices made by individuals with CD. For example, how and why are some foods eaten and others avoided? It is known that those diagnosed with CD have described their relationship with food as a "lifelong struggle" (Fletcher & Schneider, 2006); however, what is not known is how dietary fiber might relate to this struggle. Furthermore, what do individuals with CD think about the diet recommendations they receive as a component of their conventional care and the effects they experience when acting on the recommendations they are given?

Methodological strength requires that the chosen design for a study match the research questions being addressed. The questions of interest here are not easily answered using numbers and mathematical analyses. Words, not numbers, that allow for open-ended exploration of a poorly understood phenomenon—in this case, experiences of individuals with CD struggling to choose foods in the context of a disrupted digestive tract. Capturing

the participants' own words gives power to their voices (Vanderheyden, Verhoef, & Hilsden, 2006). Exploring the phenomenon before and after delivery of specific dietary information provides additional data regarding the feasibility of delivering dietary information, the receptivity of individuals with CD to the new dietary information, and perhaps insight as to the effects of dietary alterations that participants chose to make in response to information provided during the study.

Sample

Eleven individuals participated in the study. Five were recruited through a medical center-based IBD clinic after learning about the study from the gastroenterologist or gastroenterology nurse during a regular appointment. Six additional participants initiated contact with the study coordinator in response to flyers posted around the medical center and through word-of-mouth dissemination by an individual who had attended a support group meeting.

All participants met the inclusion criteria. In each case, CD symptoms had included diarrhea or rectal bleeding, and the CD diagnosis had been confirmed by colonoscopy. No participant was currently experiencing clinically significant stricturing or penetrating symptoms; was allergic to wheat; or had celiac disease, short bowel syndrome, or intestinal abscess. A partial Harvey Bradshaw Index score (pHBI) of 9 was required at baseline to exclude individuals who may have been too sick to participate in a diet study. The pHBI scores of participants ranged from '0' to '5' (average score = 2.2).

Except for age, demographic data revealed a fairly homogenous sample. The eight females and three males ranged in age from 21 to 60 years. Except for one Asian participant, all others were White and non-Hispanic. All participants had completed at least 12 years of education and most had completed at least some college education. Three of the participants had completed or would soon complete a PhD program of studies.

Intervention

The intervention consisted of a one-on-one, in-person PowerPoint presentation by the study coordinator, a nurse with 30+ years of experience working with patients with CD and diet. The presentation included pictures to help explain normal structure and function of the gastrointestinal tract and simple CD pathophysiology. Macroscopic effects of wheat bran consumption were explained including bidirectional correction of transit time and dilution of luminal irritants by the stool-bulking property of wheat bran. Microscopic effects of wheat bran consumption were then covered with participants, including an explanation about fermentation of wheat bran by beneficial bacteria which creates butyrate and other short-chain fatty acids (Pryde, Duncan, Hold, Stewart, & Flint, 2002).

Next, the benefits of butyrate and other short-chain fatty acids were explained including healing and nourishment of the intestinal epithelium, normalization of tight-junction permeability, down-regulation of nuclear factor kappa beta, and a resultant decrease in tumor necrosis factor (Kripke, Fox, Berman, Settle, & Rombeau, 1989; Ohata, Usami, & Miyoshi, 2005; Sartor, 2008; Segain et al., 2000; Sturm & Dignass, 2008). Finally, the implications regarding diet for individuals with CD was addressed. The study coordinator also shared examples of how this information has been successfully used in practice for decades to control CD symptoms in individuals with whom she worked.

Data Collection

Following protocol approval by the health system institutional review board, subject recruitment began. After participants reviewed and signed consent forms, demographic

information was collected. Participants then engaged in four one-on-one, face-to-face, semi-structured interviews that were conducted during the initial visit and two subsequent visits. The study coordinator delivered the PowerPoint presentation featuring dietary fiber information at the initial visit. Interviews #1 and #2 were conducted at the first study visit immediately before and after delivery of the PowerPoint presentation. Interviews #3 and #4 occurred at 2-week intervals following the first interview. The majority of follow-up interviews were also conducted face-to-face, although telephone interviews were conducted for one participant who was unable to return for in-person follow-up appointments. All interviews were audio recorded for later transcription and analysis.

Between appointments, each participant was free to maintain his or her current eating pattern during the study period or make dietary changes based on the dietary fiber information that had been provided. At the first and second appointments, participants were offered a 14-day Food Intake/GI Output Diary to use during the two weeks between appointments, if desired. A box of Kellogg's All-Bran Bran Buds® cereal was also offered to each participant at the first appointment. The study coordinator's contact information was provided to each participant for questions or concerns during the study. Participants received \$25.00 cash for each study visit as compensation for his/her time.

Interview Questions

Open-ended questions were used at each appointment to guide the interviews and to ensure that important areas of interest were addressed. Conversations also flowed toward specific areas of interest to each participant. The initial interview began with, "Tell me about your life with Crohn disease." Two alternative sets of questions were planned for follow-up interviews—one set of questions for individuals who chose to alter their diets and the second set of questions for individuals who chose not to alter their diets. Only the first set of questions was used because all participants chose to experiment with their diets based on the information they had received. The interview at week two began with "Can you describe your efforts to change your diet during the past two weeks?" The interview at week four started with "How is your diet going?"

Data Analysis

Transcribed audio data became verbatim textual data, which was suitable for thematic analysis using steps consistent with descriptive phenomenology (Wojnar & Swanson, 2007). The researchers first bracketed, or put aside, preconceived ideas about the phenomenon of interest and actively sought to keep an awareness of potential for bias in the analysis process. The first author read and reread the entire set of interviews, obtaining a sense of the overall feeling expressed by participants during in-depth conversations. Next, she performed initial coding, extracting significant strips from the data and pasting these strips together with other similar strips in Word documents appropriately titled to denote subject matter. This process resulted in 42 separate documents (codes) to be categorized into clusters (themes). The researchers discussed the findings, options for categorization, and overarching themes that contributed to the description of living with CD. Emergent clusters and themes were then compared to original data for validation of meaning.

Findings

Pre-intervention Themes

Two overarching themes emerged from preintervention interview data. Because previous CD treatments had failed to eliminate completely the symptoms and fears the participants held about the future, theme #1 was that the participants described how and why they were living with a redefined (lower) definition of normal health-related quality of life for

themselves compared to that held by healthy individuals. Theme #2 revealed that these participants were continuing to look for answers to eliminate their CD symptoms.

Pre-intervention theme #1: Accepting a redefined (lower) definition of normal health-related quality of life—This first theme emerged from participants' responses to the open-ended question of how CD had affected their lives. After describing initial CD symptoms, participants universally followed with descriptions of the medical, surgical, and dietary interventions they were using. They concluded by recounting the residual and lingering effects of CD for which they had no solution and which constituted their perceived lower level of quality of life.

Participants related that their pharmacological treatments had been less than totally successful at eliminating their CD symptoms. For example, one participant made the following statement about the drug Remicade when his physician brought up future treatment plans:

I said, "Fine [to plan surgery]. ... because I'm not taking Remicade anymore. ... I just had an infusion [of the Remicade] Friday and here I am back in the hospital again [with] an obstruction. We need to just go ahead and do the surgery." And so, you know, he [the physician] agreed that ... we just should go on and get it done and get it over with.

Another participant described the following experience with Imuran, the drug she was taking:

I was on a stint with Imuran, which caused severe muscle problems. ... I had taken it before and I'd always said my muscles hurt really bad. This was the first time that it had ever just seized my muscles—it just seized my muscles up. I could not walk. I could not move. I laid on the floor. ... called my family doctor. "I can't move. I don't know what to do," and I said, "How long is it going to be? I don't know how I'm going to get to the ER."

Participants had tried altering their diets to varying degrees before enrolling in the current diet study. For example, when asked if diet has anything to do with CD symptoms, one participant said, "I think that it does and I don't think that I've tried hard enough to change my diet." Two other participants had completely changed their pattern of eating in hopes of controlling their CD symptoms. Most participants had experimented to some degree with dietary manipulation. However, no participant entered the study with a completely successful and reliable answer to symptom elimination through diet alone.

For example, one participant, whose focus was on eating a healthy, well-rounded diet, considered herself in remission because she was free of symptoms. However, she was reliant on nightly steroid enemas to keep her symptoms under control. One participant suffered two partial bowel obstructions while adhering to the *Specific Carbohydrate Diet* (Gottschall, 1994). Another participant developed a fistula that resulted in sepsis while adhering to a strict diet inspired by *The Maker's Diet* (Rubin, 2004). Others had given up on diet altogether as exemplified by the remarks of the participant who noted the following:

Originally the doctor said. ... keep track of what you eat and how it affects you. Well, if every single thing you eat and drink causes the exact same thing. ... what am I supposed to do? What should I eat? What should I not eat? ... If today all I eat is this one thing and that causes diarrhea and then tomorrow I eat this and nothing but this and that causes diarrhea. ... one day you just say, "Well, you know what? It doesn't make any difference!"

As the participants considered the lingering effects of CD, they described multifaceted disruptions to their lives. Reconciling themselves to detrimental psychological and physical changes caused by CD meant accepting as normal a new (lower) level of health-related quality of life.

Participants described new physical realities, such as the participant who said: Basically it's just diarrhea all the time. You know, I just sort of stopped really thinking about it too hard and then, as long as ... I don't have, like, really bad bleeding, I just don't worry about it. I just kind of deal with it. I kind of almost don't worry too much about it if it isn't that horrible bleeding.

Another participant reported:

It's severe abdominal pain, diarrhea with the urgency of when you have to go, you have to go. There's no holdin' it or waitin' until I find a bathroom. It's "you've got to go." Blood in my stools and my bowel movements. Nausea. Just plain fatigue. You have no energy. You don't want to do anything.

A third participant noted, "It's really bad cramping, almost constant. I have a stomachache all the time."

Pre-intervention theme #2: Continuing to look for answers—The second theme emerged from participants' answers to an open-ended question regarding their personal reasons for participating in a diet study such as this one. Participants seemed to sense that there may be more for them to learn regarding CD and they were eager to find out for themselves. One participant described the following motivation:

Well, I've always been interested ... in non-medicinal ways of treating Crohns disease. ... and now I'm going to be moving on to Imuran, which is going to suppress my immune system and ... I am somebody who is constantly sick all the time anyway [with] pneumonia, strep throat, so ... it was really important to make time for this to see if there is anything natural that can help me and I'd be crazy not to pursue that.

Another participant described the following:

This is an important issue in my life. ... I mean it's self-preservation in some sense and I'm nervous that ... that it could actually take away life or make life so constrained and miserable that it's not much of a life. So, yeah, I'll do just about anything to, you know, to try to fix Crohns.

Although the details of their stories varied, these two themes were consistent. First, the individuals who participated in this study were all living with new realities defined by unresolved CD-related physical symptoms and/or new CD-related psychological burdens. Second, their participation in this diet study and their reasons for that participation spoke of an underlying hope that there is more to be figured out regarding the troubling symptoms of CD. The participants in this study were eager to find a new way to help themselves.

Post-intervention Themes

Participants' second interviews were conducted immediately following the dietary fiber PowerPoint presentation. In summary, 100% of participants reported in the second interview that the dietary fiber information was new to them, it made sense to them, they understood it, and they intended to experiment with associated dietary alterations during the 28-day study period. Each participant expressed in his or her own words cautious optimism and a desire to "give it a try" and "see for myself." Some participants asked questions and sought to clarify further their understanding of the information and its implications. Others

immediately planned meals and shopping lists. All participants accepted the 14-day Food Intake/GI Output diary and the box of cereal and stated their intention to try using both.

Three post-intervention themes emerged from interview data collected at the two follow-up visits. Participants communicated that they were (a) re-evaluating old diet-related concepts, (b) enjoying a healthier lifestyle at a self-set pace, and (c) enjoying physical effects of wheat bran consumption. This article highlights the third post-intervention theme, “enjoying physical effects of wheat bran consumption.”

Post-intervention theme #3: Enjoying physical effects of wheat bran

consumption—Because participants were experiencing a variety of symptoms at baseline, reported benefits of wheat bran consumption also varied. Some CD-relevant systemic symptoms such as joint pain continued during the study. However, among the effects participants enjoyed were (a) reduction and/or elimination of diarrhea, (b) reduction and/or elimination of pain/cramping, (c) reduction and/or elimination of urgency and incontinence, and (d) elimination of borborygmus (stomach gurgling). Not all participants entered the study with all of these symptoms; however, participants in the study reported reduction or elimination of the CD symptoms that they had at the point of the study entry.

For example, one participant with constant pain reported her pain relief as follows:

I’m sure the bran has definitely helped because I move my bowels more regularly, more normally. I don’t have that terrible cramping, inefficient cramping where it felt like it was trying to work but it wasn’t working ... [my bowels are functioning] a lot better, a lot better with the bran cereal. Yeah, I’m real happy about it. I am.

Another participant had been experiencing chronic diarrhea and described her symptom relief as follows:

Within the first week I had a solidly formed stool without, you know, [prednisone]. First time in three years! ... It was actually kind of cool! I actually ran out of the bathroom and I told my husband ... “You will never believe what just happened!”

Another participant who had struggled with diarrhea and cramping before consuming the bran said, “My stools are formed, normal stools ... they pass easily. ... I’ve been doing well with the bran and the fiber.”

Several participants entered the study suffering with tenesmus, the constant feeling of needing to empty the bowels even when no stool is present. One participant described improvement compared to her functioning prior to wheat bran as follows:

Before, I was having to get up and spend extra time in the mornings, you know, going to the bathroom and never knowing what time I was going to make it to work. And so now, you know, the diarrhea has slowed down a lot and I’m actually forming normal stools, so I really see a big improvement.

Several participants associated the physical effects of wheat bran with the restoration of prior freedoms they had. For example, one participant described her restored freedom as follows:

Yeah [it gives me more freedom]. ... I can go out and do different things and not need to know exactly where the bathroom is and ... how fast I can get there. So it’s given me a lot more freedom to do those types of things.

Freedom from embarrassment was also implied as one participant expressed pleasure resulting from the following observation:

I haven't had the worry about losing bowel when I have gas. So that has been a wonderful treat. ... to not have to wonder ... have I dirtied my pants? ... that's been a wonderful feat as far as that goes with having the control.

Still another participant described restoration of her freedom as the ability to perform everyday activities that had been difficult prior to participation in the study because of uncontrolled CD symptoms. She said, "Oh, [I feel] free. ... I know that, okay, when I walk the dogs and I have the urge [to go to the bathroom], I can wait until I get back, whereas before I didn't know."

Several participants were pleased that their body weight was beneficially altered during the study. One participant was pleased to be gaining weight, presuming that decreased intestinal inflammation was promoting nutrient absorption. He said, "So I'm ... happy to be gaining weight. ... I was actually starting to get nervous about ... wasting away into nothingness basically. So, overall, I'm happy about that [weight gain]."

In contrast, another participant was pleased to have lost weight during the first two weeks of the study, presuming that satiety on the high fiber diet caused her to eat less. She said, "I want to tell you I have weighed myself ... and in the last two weeks I have lost 6 pounds! So I am very excited, because for me that is not easy."

Borborygmus, audible intestinal gurgling characteristic of active CD, was also present in participants prior to the study. One participant was pleased to report resolution of this symptom. She said, "My stomach and everything just feels completely better down there. It's not rumbling all the time or making noises at me. ... so, yeah, that has been wonderful."

Toward the end of the study, the physical benefits enjoyed by these participants included a general improvement in sense of well-being, especially energy level. For example, one participant made the following observation about her activity level while participating in the study:

Overall I just feel ... healthier and I also feel like I have a lot more energy. Like, I could not have done a 9-mile bike ride ... a couple of months ago [as she had mentioned she did the prior week while on vacation].

Another participant categorized fatigue as one of her most debilitating symptoms prior to participation in the study, and she described improved general well-being as follows:

But my biggest symptom was being fatigued and the body aches and things like that, and that's really improved. I've got a lot more energy. So energy's up. The body aches have really almost gone completely away. I had a lot of hip pain and a lot of shoulder pain. That's gone.

A third participant described the change in her energy level and general well-being as follows:

I have a lot more energy. I do see a change in the way I feel ... so I feel like it [the bran] is working and improving my health ... I started walking ... before, I always wanted to exercise and walk, but was just so tired. ... I just wanted to lay in the bed ... but ... I feel a little bit better so I try to walk every day when I get home and I really have seen a difference. So, [it makes me feel] great ... it really does, especially since the never-ending cycle I was in. It feels good to know there's a light at the end of the tunnel.

Discussion

This study provides new knowledge about what can happen when individuals with CD receive relevant dietary fiber information from a healthcare professional. Individuals in this sample found the information to be applicable to their daily lives as they sought to upgrade their lifestyles to include a more nutritious, well-rounded diet. Ten of the participants in this study had previously thought dietary fiber was contraindicated for CD. During the study, all 11 participants verbalized a new reconceptualization of dietary fiber as an important and beneficial food component, especially in the context of CD. As a result, they found ways to incorporate concentrated wheat bran cereal and other sources of fiber into their daily habits.

The participants embraced their new-found relationship with dietary fiber with gusto. Their conversations covered a wide range of topics, including renewed joy in cooking, relief in being able to return healthy whole grains to the family dinner table so that their children will develop healthy eating habits, and satisfaction in creating ways to pack All-Bran Bran Buds® cereal for domestic and international travel, thus insuring its availability wherever their travels took them. The enthusiasm of these study participants is rippling outward and influencing family, friends, and co-workers. One participant used her study payment to purchase boxes of cereal that she gave to her gastroenterologist after the study concluded, encouraging him to give it to other individuals in his practice who suffer with CD.

The findings of this study are consistent with findings of other studies of persons diagnosed with CD. For example, Fletcher and Schneider (2006) found food consumption to be the most significant issue for participants in a sample of women with IBD or irritable bowel syndrome. Jamieson, Fletcher, and Schneider (2007) also found that patients' "dissatisfaction with conventional medical treatments and experiences with side effects from various treatments" (page 159) motivated their participants to focus on dietary alterations to manage symptoms in a similar sample of women. Finally, Cooper, Collier, James, and Hawkey (2010) found in their sample of individuals with IBD that participants believed it was beneficial to have "active personal control over the course of IBD" (p. 1506).

Limitations of the Study

This study is limited by several factors. First, although all participants in this study reported improvement in gastrointestinal function following dietary alterations made during the course of this four-week study, no causal association can be concluded. The design of the study prevents any conclusions other than that of the participants' interpretations of their level of functioning. Furthermore, the results from this study which included homogenous and well-educated adults cannot be generalized to the wider population of individuals with CD that includes a heterogeneous mix of phenotypic expressions of CD.

Recommendations

Two recommendations seem justified by the findings of this study. First, gastroenterology nurses should consider equipping themselves with the latest in dietary fiber information to ensure that they can lead the way in helping patients with CD to adopt a healthy appreciation of the nutritious and well-rounded diet that includes dietary fiber. Second, more robust investigation of the inadequately tested IBD-fiber hypothesis of the 1980s should follow this demonstration of acceptance, tolerance, and appreciation of a fiber-rich diet by individuals with active CD symptoms.

Conclusion

The current study succeeded in systematically exploring the feasibility and effect of offering dietary information as an adjunctive intervention to a sample of individuals with CD. The results demonstrate that these participants were able to process and use the information to make changes in their daily diets that they viewed as beneficial to their health. No side effects occurred with the addition of concentrated wheat bran cereal and reduction of refined carbohydrates in the study participants. Participants appreciated being provided information and given the opportunity to use the information or not, and they appreciated the time spent by a health care professional to help them delve deeply into the complex relationship between food and the symptoms of CD. In the end, participants in this study valued the opportunity to judge the effects of concentrated wheat bran cereal consumption for themselves.

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