



Published in final edited form as:

J Clin Gastroenterol. 2012 February ; 46(2): 138–144. doi:10.1097/MCG.0b013e318225f545.

How Patients View Probiotics: Findings from a Multicenter Study of Patients with Inflammatory Bowel Disease and Irritable Bowel Syndrome

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Abstract

Background—Patients with inflammatory bowel disease (IBD) and irritable bowel syndrome (IBS) have access to a growing number of probiotic products marketed to improve digestive health. It is unclear how patients make decisions about probiotics and what role they expect their gastroenterologists to play as they consider using probiotics. Understanding patients' knowledge, attitudes and expectations of probiotics may help gastroenterologists engage patients in collaborative discussions about probiotics.

Study—Focus groups were conducted with patients with IBD and IBS at the Cleveland Clinic, Mayo Clinic and Johns Hopkins University. Inductive analytic methods were utilized to identify common themes and draw interpretations from focus group narratives.

Results—One hundred thirty-six patients participated in 22 focus groups between March and August 2009. Patients viewed probiotics as an appealing alternative to pharmaceutical drugs and understood probiotics as a more “natural,” low-risk therapeutic option. Many patients were hesitant to use them without consulting their gastroenterologists. Patients would weigh the risks and benefits of probiotics, their disease severity and satisfaction with current treatments when considering probiotic use.

Conclusions—Patients are interested in probiotics but have many unanswered questions about their use. Our findings suggest that patients with IBD and IBS will look to gastroenterologists and other clinicians as trustworthy advisors regarding the utility of probiotics as an alternative or

supplement to pharmaceutical drugs. Gastroenterologists and other clinicians who care for patients with these diseases should be prepared to discuss the potential benefits and risks of probiotics and assist patients in making informed decisions about their use.

Keywords

probiotics; patient communication; ethics

Introduction

Patients with inflammatory bowel disease (IBD) and irritable bowel syndrome (IBS) have ready access to a large and growing number of over-the-counter probiotic products (1,2). The convenience of patients' access to these products, their low cost in comparison to pharmaceutical drugs and the ongoing challenges of managing these diseases may encourage patients to try probiotics as an alternative or supplement to standard pharmaceutical therapies (3–5). These considerations suggest that clinicians who care for patients with IBD and IBS should anticipate that many will have tried probiotics or have questions about their potential usefulness as a treatment option. Systematic data on patients' views of probiotics can provide insights on how best to engage patients in clinical discussions about probiotics and their use in the management of IBD and IBS (6).

Although many gastroenterologists view probiotics as generally safe (7), there are risks associated with probiotic use, particularly for patients who are immune compromised (8). Some data exists to support the use of probiotic bacterial strains for the treatment of IBS, pouchitis, and ulcerative colitis (9–13), but there is weak scientific evidence to support their use in the treatment of Crohn's disease (13,14). To help gastroenterologists prepare for clinical encounters with patients interested in using probiotics, we present findings from a qualitative study of patients' perspectives on probiotics. The aim of this study was to describe how patients with IBD and IBS conceptualize probiotics and make decisions about their use. We also sought to characterize other considerations relevant to clinical discussions of probiotics, including patients' familiarity with probiotic products, beliefs about their potential benefits and risks, and willingness to use probiotics.

Materials and Methods

Study Design and Sample

We conducted focus groups with adult patients with two main chronic GI diseases, IBD and IBS, for which probiotics are sometimes used as therapy. A focus group discussion is a research method that uses group interaction to gather data on a specified topic of interest (15). We chose this method because it is ideal for gathering in-depth data on topics that have not been extensively studied (16). The group dynamic also facilitates expression of a variety of personal experiences and opinions in patients' own words, providing researchers with rich data that may not otherwise be captured (15,16).

Patients were recruited from the Cleveland Clinic Digestive Disease Institute, the Inflammatory Bowel Disease Clinic at Mayo Clinic, and the Division of Gastroenterology at Johns Hopkins University. Eligibility criteria consisted of patients with IBD, including pouchitis or with IBS who were seen at one of the three specialty clinics within the past two years. In addition, patients had to be at least 21 years of age, proficient in English, and able to provide informed consent for study participation. Recruitment was tailored to the unique features of the gastroenterology clinics at the three study sites. Researchers at Cleveland Clinic and Johns Hopkins recruited patients through direct mailings to patients seen in gastroenterology clinics. Gastroenterologists providing care to patients with IBD, IBS and

pouchitis also introduced the study to eligible patients and those who wished to participate contacted a study coordinator for additional information. At Mayo clinic, a nurse coordinator in the IBD clinic recruited eligible patients by telephone.

To enhance patients' comfort and promote group interaction during focus groups, we grouped patients with common disease experiences. At each study site we sought to conduct a minimum of six focus groups: three disease specific groups (respectively composed of patients with Crohn's disease, ulcerative colitis, and IBS) and three mixed-diagnoses groups. Patients with Crohn's disease and ulcerative colitis reported similar disease experiences during our early focus groups and thus we grouped patients with these diseases together in later focus groups, along with patients with indeterminate IBD.

Data Collection

After providing informed consent, patients completed an anonymous demographic questionnaire prior to each focus group. Specialists in qualitative research co-moderated all focus groups (MBM and MB at Cleveland Clinic; JM and JT at Mayo Clinic; GG and KH at Johns Hopkins). Moderators used a structured list of open-ended questions covering topics such as perceived benefits and risks of probiotics, sources of information and willingness to use probiotics to facilitate discussion. After exploring patients' baseline familiarity with probiotics, moderators provided a working definition of probiotics to guide the discussion, typically using the following language, "foods or supplements that contain large amounts of 'friendly' bacteria that are intended to improve digestive health." In addition to discussing currently available over-the-counter probiotic products, moderators examined patients' views of probiotics administered in clinical research and those that may be available in the clinical arena in the future. Data collection continued until we achieved content saturation.

Data Management and Analysis

Focus group recordings were transcribed verbatim and each transcript was reviewed by a member of the research team for accuracy. Four data analysts employed inductive methods drawn from grounded theory (17) with three focus group transcripts, one from each study site, to identify initial themes in the focus group narratives. Using an iterative process of independent review and consensus-building meetings, we created a coding schema to categorize the text into major domains, subdomains, and categories. In addition, researchers from each site composed a thematic summary outlining major content areas from their focus group discussions. The entire research team then reviewed the thematic summaries and preliminary coding schema and revised the coding schema based on these discussions. Two data analysts applied this coding schema to a second set of three transcripts using QSR NVivo 8 (18) and made minor modifications based on this experience. All focus group transcripts were coded independently by two data analysts who met to review their respective codes and resolve any discrepancies. We then used standard inductive techniques (17) to generate thematic interpretations of coded transcripts. We used SPSS 16.0 (19) to calculate descriptive statistics on demographic items.

Human Subjects Protections

This research protocol and all study materials were approved by the Institutional Review Boards at each of the three study sites. Written informed consent was obtained from all patients prior to focus group discussions. Patients received \$50 for their participation in the study. Patients were not identified by name in focus group transcripts.

Results

We conducted twenty-two focus groups at the three study sites between March and August 2009. Group composition by patient diagnosis was as follows: 8 groups with mixed diagnoses; 8 groups with IBD; 3 groups with IBS, 2 groups with Crohn's disease, and 1 group of patients with ulcerative colitis. Three groups included all women and 1 group all men. Demographic characteristics of patients are summarized in Table 1.

Familiarity and Experience with Probiotics

Patients had varying degrees of familiarity with probiotics. Some patients had never heard the term while others had some knowledge of them. Of those who were familiar with probiotics, most associated the term with yogurt, live active cultures, good bacteria, and digestive balance. Many patients reported having first heard about probiotics in television commercials advertising yogurts and other over-the-counter probiotic products.

Patients had some knowledge of how probiotics function in the digestive tract. They understood that probiotics work by adding bacteria that may be absent and restoring good bacteria to the digestive tract.

[My disease]...it's an overgrowth of bad bacteria. We've all got good bacteria in our bodies to control the bad bacterias that are naturally present in us, and so it's just about a balance in there. And they're talking about supplementing some good bacteria to sort of handle the bad bacteria so our immune system doesn't feel like it has to.

Some patients had used or currently were using over-the-counter probiotic products, such as probiotic foods (yogurt, kefir) and supplements (pills), with varying results. Some reported relief from their symptoms and an improvement in how they felt after using probiotics.

I don't have the gut cramps that I used to. I don't have the burning, 'Oh my God, my ileum's going to fall out' feeling...I don't feel 'ouchy' and as sensitive if I press my own abdomen. It doesn't hurt so much any more...

Others noticed no improvement in their symptoms while using probiotics or reported experiencing side effects from probiotics such as bloating and cramping.

Conceptualizations of Probiotics

The manner in which probiotics are ingested impacted patients' conceptualizations of them. Patients often associated probiotics with yogurt products and viewed them as food. They noted the expansion of both the yogurt section at grocery stores as well as the number of food products containing probiotics. Patients frequently drew analogies between probiotic pills and vitamins or other nutritional supplements. They viewed probiotic pills as a supplement of good bacteria for the digestive tract which would improve its function similar to how calcium, for example, is taken as a supplement to support healthy bones.

I view probiotics as kind of benign thing. I don't think they will harm you...But if it's part of your body naturally, same as vitamins, if you take a vitamin and your body doesn't need it, it just doesn't absorb it and it passes through. If you take a probiotic and your body doesn't need it, it just passes through.

Some patients also drew distinctions regarding the scope of impact in the body when comparing probiotics to vitamins. These patients viewed the effect of probiotics as gut-specific, whereas the impact of vitamins was viewed as systemic.

Patients tended to view probiotics as “natural” because they are living organisms that normally reside in our digestive tracts. Patients described their digestive tracts as unbalanced and expressed a desire to return to a healthier state of balance. They viewed probiotics as “natural” products that would restore the good bacteria that are depleted in their gut, without causing harmful side effects.

Evaluating the Benefits and Risks of Probiotics

Patients drew upon personal disease experiences when discussing probiotics as a therapeutic option. They often evaluated probiotics by comparing and contrasting them to pharmaceutical drugs they had used previously or were currently using to manage their disease. In this respect, pharmaceutical drugs were the primary interpretive frame of reference for patients evaluating probiotic options.

Some patients reported that pharmaceutical drugs worked well for them while others noted that medications had been ineffective in treating their disease. Patients expressed frustration about what they considered “a hit or miss” approach with pharmaceutical drugs.

So has everybody here kind of gone through, you know, a variety of medications? ‘We’ll try this and see if it works,’ and it doesn’t so you throw it [out], and then, ‘try this and see if it works,’ and, finally, you come across one that probably works. I mean, don’t you just feel like you’re just testing them all sometimes?

Many patients also expressed frustration that their medications had worked initially but became less effective over time. Uncertainty about the long-term effectiveness of pharmaceutical drugs left many patients with concerns about future treatment options. Probiotics were appealing to these patients because they were viewed as offering another potential therapeutic approach for patients who felt they may be running out of pharmaceutical options.

Patients were very concerned about the short- and long-term side effects of drugs and noted that at times the side effects of their medications were worse than the disease. They tended to view drugs as chemical, synthetic and toxic, with a high level of risk for side effects. Patients also expressed concerns about the high cost of pharmaceutical drugs and potential for adverse drug interactions. Overall, patients expressed a desire for cheaper, less burdensome, more “natural” alternatives to pharmaceutical drugs.

Despite this high level of interest in alternatives to pharmaceutical drugs, patients frequently expressed skepticism about the potential usefulness of probiotics as a viable alternative. Their skepticism about probiotics was based on the lack of recommendations by their physicians, minimal governmental regulation of probiotic products, and what many patients regarded as limited empirical evidence in support of probiotic efficacy. Typical in this regard is one participant’s comment that:

...my personal opinion is that if it worked, then the FDA, pharmaceutical companies, physicians would be recommending these and would have recommended them a long time ago and we would all know about it...there would have been clinical trials that had shown evidence and significant evidence demonstrating that these worked. And to date, there are no clinical trials demonstrating effectiveness of the probiotics in relation to medications or better effectiveness in relation to medications. And thus, I’m not willing to run out and buy yogurt, or any other capsules or whatever.

As a result, despite numerous concerns about the costs and burdens of pharmaceutical drugs, patients generally were reluctant to abandon medications with established effectiveness for probiotic alternatives where efficacy remains uncertain.

Some patients expressed similar concerns that probiotics had not been evaluated for safety in people with chronic GI diseases. Patients perceived probiotics as safe products for use by the general public but were concerned that probiotics might present higher risks for individuals with GI diseases. They also expressed concerns about potential interactions between probiotics and pharmaceutical drugs.

...For those of us who do have a clinical condition, circumstances might be different than for the general public to whom some of these over-the-counter things are marketed. In addition, if we already take some prescription medications, we have concerns about what the interplay might be of those with these.

Some patients also expressed concerns about the quality of probiotic products. For example, patients sometimes questioned whether product labels accurately described the bacterial strain(s) and amount of bacteria contained in probiotic products.

I have diffidence though as to what we are getting when we buy all this medicine, the probiotics or whatever. I somehow don't feel like we're getting the real thing. I somehow feel like we are being duped, perhaps because I never felt any real relief.

Perceived variability in quality across commercial products shaped perceptions of the overall benefits and risks of using probiotic products.

Making Decisions about Probiotics

Patients reported that the severity of their disease and their satisfaction with current treatments would be important considerations when making decisions about using probiotics. Patients' willingness to try probiotics would be affected by the severity of their disease at any given time.

This is a very desperate population of patients that is just seeking an answer, you know, and I think we're willing to reach out to anything.

Patients said they would be very hesitant to change their disease management plan when they are feeling well and would be reluctant to alter anything that could tip the scales in the direction of experiencing a flare up of their disease. Patients also spoke of considering the effectiveness and side effects of pharmaceutical drugs they are taking when making decisions about probiotics. If their drugs are effective in managing their disease, with few to no side effects, they would be less likely to consider using probiotics. If they are dissatisfied with the effectiveness of their drugs, or are experiencing numerous side effects, they would be more likely to consider using probiotics.

Some patients talked about how they were running out of pharmaceutical options for their disease. For them, probiotics would be a worthwhile treatment to try in hopes of feeling better.

... it's like a drowning person and you grab the hand. I mean, if you're going down, there's something wrong and if the doctor says 'we're doing everything we can for your system, but unfortunately gastroenterology can only do so much – there's only so much we know. There is a lot we don't know.'

For these patients, probiotics would be an option when standard therapies were no longer effective.

The Need for Comprehensive Information from Reputable Sources

Patients reported having learned about probiotics from the internet, advertisements, family, friends, and health care providers. Although patients viewed the internet as a convenient

source of information about their digestive diseases, they expressed concerns about the quality of medical information available on the internet.

The problem with the internet is that it can be helpful but it can also be deceitful because anyone can put anything out there and sometimes you have to kind of decide for yourself if that information is accurate or not.

Patients who had read patient blogs or had participated in chat rooms also expressed concerns about the quality of that information because they felt their personal disease experience was unique and what may have worked for other patients might not work for them.

Patients consistently expressed a desire for more information about probiotics, including their composition, how they function in the digestive tract, their risks and benefits, and how probiotics might fit into their treatment regimen. For example, patients wondered if they would have to go off of their current medications to take probiotics and expressed reluctance to abandon their current drugs altogether. While patients hoped that probiotics would be effective, many expressed doubts that probiotic products could manage their disease as well as pharmaceutical drugs. As one patient commented,

I would have to know that it is more than just like eating yogurt. Because, I think if I stopped all my medicine and just ate yogurt at every meal that I would have some problems. So I would have to know that this is not just about a quick little diet change, but it is something that would really help me just like the medicine would.

Patients drew distinctions between information about probiotics targeted to the general public, many of whom have occasional digestive problems, and information about the use of those products by people with chronic digestive diseases. Patients felt that information from popular media, such as television commercials, is incomplete and of questionable quality since the purpose is to sell products. They expressed a desire for more information about the use of probiotics in the management of GI diseases, such as safety and efficacy data from research studies.

I just don't have access to real research to know 'okay, is it good for keeping you in remission or making you feel better or is there a specific one for specific types of diseases?' So I just feel like I'm flying a little bit blind with the information.

They consistently expressed a desire for comprehensive information about probiotics from scientists and medical professionals.

A Desire to Partner with Gastroenterologists

Some patients had sought information and advice about over-the-counter probiotics from their health care providers, including gastroenterologists, primary care physicians, nurses and pharmacists and reported mixed experiences. Patients typically reported that their gastroenterologists informed them that while there is not a lot of scientific evidence to support the use of probiotics for disease management, some of their patients had tried probiotics and found them to be helpful. In addition, gastroenterologists were reported to have advised patients that using probiotics probably would not hurt them, despite the uncertain evidence of benefit.

I talked it over with my physician...we decided, 'Yeah, let's give it a shot. Everything else is kind of up and down for you, so let's see if some [probiotics] will work.' So, it was kind of a decision together.

A few patients noted that their gastroenterologists advised them not to try probiotics, either because a diagnosis was not yet made or because their current treatments were effective.

Overall, patients expressed a desire to partner with their clinicians in deciding if probiotics may be appropriate for use. Many patients viewed their GI clinicians as trustworthy sources of information and guidance about probiotics and expected that their gastroenterologists would have the most up to date information on emerging treatment options. Patients also viewed their gastroenterologists as knowledgeable about their disease and in the best position to determine if probiotics were a good therapeutic option given each patient's unique disease experience.

I trust my doctor first...I've read about it [probiotics] on the internet, but I wouldn't trust what I read there so I asked him before I did anything.

While most patients expected their clinicians to have current information about new therapeutic options, some believed their doctors were not very well-informed about probiotics. These patients acknowledged that this might be due to a lack of evidence regarding the effectiveness of probiotics or greater familiarity with standard pharmaceutical therapies for treating chronic GI diseases. Other patients felt that their clinicians might be dismissive of their interest in probiotics.

My experience with doctors, when it comes to things like this, is as long as they know that it isn't harmful to you they will kind of shrug and go, 'Sure, go ahead and try it.' You know, just a kind of a dismissing of the idea of something that isn't on a prescription pad. As long as they know that it won't hurt you...that they can say in good conscience that it won't be bad for you. That is my experience with them.

Overall, patients viewed their gastroenterologists as ideal partners in managing their disease but not always equipped to engage fully in a patient-centered dialogue about alternative therapeutic options. They expected their gastroenterologists to be knowledgeable about probiotic options and open to considering probiotics as a supplement to ongoing treatments.

Although patients viewed their physicians as ideal partners in clinical decisions, many also viewed probiotics as an attractive way to manage their disease without the involvement of a clinician. Some patients spoke of gaining a sense of control over their disease and improving their overall quality of life as a result of this self-management approach.

The way probiotics are now, it is something that your doctor is not going to prescribe so you have to actively seek [probiotics] and at least talk to your doctor about it. So, just through doing that I think you would feel more in control of what is going on and at least that would make me feel better.

Some patients felt that a self-care approach, of which probiotics might be one part, also would allow them to step outside of their identity as a sick person to some extent.

Discussion

Our findings suggest that patients with IBD and IBS are interested in using probiotics to improve their digestive health. Patients in our study found probiotics appealing because they perceived them as more "natural" and more accessible than pharmaceutical drugs and understood them to have little or no risk of side effects. Given the availability of over-the-counter probiotic products and numerous direct-to-consumer advertisements that appear on television and in other media, patients with IBD and IBS will likely be aware of probiotic products. As a result, gastroenterologists and other clinicians who care for patients with these diseases should expect that many of their patients are using or may be interested in using probiotics and that this interest may increase over time as new products are introduced into the marketplace.

Although patients had varying levels of familiarity with probiotics, most wanted additional information from their clinicians, particularly data on probiotic effectiveness and safety in patients with IBD and IBS. The paucity of randomized controlled trials and variable evidence of efficacy of probiotics in patients with IBD and IBS (9–14) could pose challenges for gastroenterologists and patients seeking sound data to inform therapeutic decisions. The apparent disconnect between the gold standard of evidence-based care and the anecdotal evidence about probiotics patients bring to the clinical encounter, may create tensions between patients and their gastroenterologists. Patients want to speak with their clinicians about the potential applicability of probiotics for their specific clinical challenges and gastroenterologists are well-positioned to facilitate that conversation, drawing on available scientific data while acknowledging the limitations of those data as the basis for treatment recommendations. Such an open and honest exchange would likely result in increased satisfaction with the clinical encounter for both clinicians and patients.

While patients in our study rarely referred to probiotics using the term “complementary and alternative medicine” (CAM), their perception of them as alternatives to standard treatments is consistent with the definition used by the National Center for Complementary and Alternative Medicine (20). The use of CAM is common among patients with IBD (3,4,21) and patients seek CAM for a variety of reasons including deleterious side effects and lack of effectiveness of standard pharmaceutical therapies as well as the desire to participate more in the management of their disease (4,5,21). Patients in our study were interested in probiotics for similar reasons but expressed concerns about their clinicians’ receptivity to their exploration of alternative therapies. Patients want their clinicians to be open to considering probiotics rather than outright dismissing them, regardless of their attitudes and beliefs about the clinical utility of probiotics. Patients perceived real value in partnering with their clinicians in exploring all therapeutic options, conventional or otherwise. Gastroenterologists who view probiotics as outside the scope of their clinical practice risk alienating their patients, many of whom are seeking knowledge and guidance from specialists they trust and who are familiar with their unique disease experiences.

Although patients expressed a preference for more “natural” low risk therapeutic options, their desire to feel well influenced their acceptance (albeit sometimes with reluctance) of pharmaceutical drugs with proven benefits and known risks. Patients in our study hoped probiotics would be effective in treating their disease but their expectations for benefits were modest. Their hesitancy to abandon their medications for probiotics suggests that patients will be more likely to consider using probiotics in conjunction with conventional pharmaceutical drugs rather than as an alternative to their medications. This may present opportunities for gastroenterologists to explore probiotic use within the parameters of standard therapeutic approaches to disease management. Gastroenterologists may be reassured that many patients want to use probiotics as a complementary therapy, under a physician’s supervision.

Patients in our study indicated that disease severity and satisfaction with current treatments would be key factors in their decision-making about probiotic use. This finding suggests that patients may have a higher tolerance for risk when they are not feeling well and thus be more likely to try probiotics at that time. For example, patients may inflate the potential benefits and minimize the risks of using probiotics when they are desperate to feel better, possibly compromising informed decision-making. To ensure that patients understand the potential benefits and risks of using probiotics and optimize informed decision-making, gastroenterologists may find it useful to introduce discussions of probiotic options proactively at times when patients are not experiencing exacerbations of their GI disease.

Data from a recent survey by Williams and colleagues suggest that practicing gastroenterologists view probiotics as having at least some role in the treatment of GI diseases (7). This same study found that most gastroenterologists acknowledge the scarcity of scientific data on the effectiveness of probiotics in the treatment of IBD. These data highlight the need for clinical trials and practice guidelines on the use of probiotics in gastroenterology (7). Evidence-based practice guidelines will become increasingly important as new research data emerge, patient interest in probiotics grows, and clinicians find themselves in the position of helping patients navigate numerous probiotic options. In addition to data on probiotic efficacy, it would be equally helpful to devise and test tools to facilitate more collaborative conversations about that evidence.

Additional research is needed to characterize patient opinions about the use of probiotics in the treatment of IBD and IBS. Specifically, quantitative data gathered via surveys from a larger patient population could better characterize knowledge and opinions about probiotics as well as patterns of probiotic use and interactions with clinicians. In addition, research is needed to explore the knowledge and opinions of gastroenterologists regarding over-the-counter probiotic products and their impact on clinical care. Both trajectories of research would likely provide valuable insight into how to optimize patient-clinician communication and decision-making about probiotics.

There are limitations to our study related to our sample and methods of inquiry. Our study sites were all tertiary care hospitals in the U.S. with large centers known for excellence in treating patients with digestive diseases. The views expressed by these patients may not be typical of other patients with IBD and IBS. In addition, patients who self-selected to participate in our focus groups may have greater knowledge or a more favorable attitude about probiotics in comparison to patients who chose not to participate. Finally, there are inherent limitations with a focus group approach, such as the potential to inhibit dissenting opinions and overstate levels of agreement.

To keep pace with increasing patient interest and demand for probiotics, it is important for clinicians who care for individuals with IBD and IBS to understand how patients view probiotics and make decisions about their use. Our study illustrates that patients conceptualize probiotics as a generally benign therapeutic option that may help manage their digestive disease when used in conjunction with pharmaceutical drugs. Many patients are willing to try probiotics but have unanswered questions about their potential benefits and risks. Patients with IBD and IBS want additional information about probiotic therapies and will likely look to their gastroenterologists for guidance about their use. Understanding patients' knowledge, attitudes and expectations about probiotics can help clinicians engage their patients in collaborative discussions about the use of probiotics in the management of these chronic GI diseases.

Acknowledgments

We appreciate Drs. Edward Loftus' and Gerard Mullins' contributions to the study. We thank the study volunteers who generously gave their time to share their experiences and opinions with us.

This work was funded by grant number R01HG004877 from the National Human Genome Research Institute.

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Table 1

Characteristics of Patients (n=136)

Age mean \pm SD years (range)	48 \pm 16 (21–88)
	n (%)
Gender	
Female	91 (67)
Male	45 (33)
Education	
Less than high school	3 (2)
High school/GED	23 (17)
Community college	34 (25)
Four-year college	43 (32)
Graduate school	28 (21)
Professional school	5 (4)
Income*	
Less than \$15,000	11 (8)
\$15,001–35,000	17 (13)
\$35,001–55,000	27 (21)
\$55,001–75,000	23 (18)
\$75,001–100,000	25 (19)
Over \$100,000	28 (21)
Ethnicity*	
Non-Hispanic	127 (96)
Hispanic	5 (4)
Race*	
White or Caucasian	126 (93)
Black or African American	4 (3)
American Indian or Alaska Native	1 (1)
Asian	1 (1)
Multi-racial	3 (2)
Self-Reported Diagnosis*	
Crohn's Disease	47 (35)
Ulcerative Colitis	33 (24)
Pouchitis	6 (5)
Indeterminate IBD	3 (2)
Irritable Bowel Syndrome	38 (28)
Other/unknown diagnosis**	8 (6)

Health Insurance*	
Yes	128 (96)
No	6 (4)
Previous participation in research*	
Yes	64 (47)
No	71 (53)
Patients across clinical sites	
Cleveland Clinic	55 (40)
Mayo Clinic	53 (39)
Johns Hopkins	28 (21)

* Some patients did not provide this information.

** Two patients reported a diagnosis of small intestinal bacterial overgrowth and one reported a diagnosis of *Clostridium difficile*. Five patients reported they had no diagnosis to date.