



Published in final edited form as:

Inflamm Bowel Dis. 2012 April ; 18(4): 676–684. doi:10.1002/ibd.21775.

Fecal Bacteriotherapy for Ulcerative Colitis: Patients Are Ready, Are We?

Stacy A. Kahn, M.D.¹, Rita Gorawara-Bhat, Ph.D.², and David T. Rubin, M.D.³

¹University of Chicago Inflammatory Bowel Disease Center Department of Pediatrics Section of Pediatric Gastroenterology, Hepatology, & Nutrition MacLean Center for Clinical Medical Ethics 5841 S. Maryland Ave., MC 4065 Chicago, IL 60637

²University of Chicago Department of Medicine Section of Geriatrics and Palliative Medicine 5841 South Maryland Ave., MC 6098 Chicago, Illinois 60637

³University of Chicago Inflammatory Bowel Disease Center Department of Medicine Section of Gastroenterology MacLean Center for Clinical Medical Ethics 5841 S. Maryland Ave., MC 4076 Chicago, IL 60637

Abstract

Background—Fecal bacteriotherapy (FB) has been proposed as a safe and effective alternative treatment for a number of gastrointestinal conditions including ulcerative colitis (UC). We performed a qualitative study to explore the attitudes and concerns of adult patients and parents of children with UC regarding FB as a potential treatment.

Methods—We conducted 6 focus groups for adult patients with UC and parents of children with UC or indeterminate colitis. Participants were asked about their perceptions of and interest in FB as a treatment for UC. Sessions were recorded, transcribed, and reviewed to identify domains, themes, and major concepts.

Results—The focus groups included 15 adult patients and 7 parents of children with colitis. We identified 5 major domains pertaining to fecal bacteriotherapy: impressions of treatment, benefits, risks, potential mechanisms, and social concerns. All but one participant expressed interest in FB and several wished it were already available. Participants compared FB to probiotics, felt it was “natural”, easier than current therapies, and with donor screening would be safe. Although initial distaste and the “yuck factor” were uniformly mentioned, these concerns were outweighed by perceived benefits.

Conclusion—This is the first study to examine important ethical and social issues surrounding fecal bacteriotherapy as a treatment for ulcerative colitis. Given adequate supporting research, donor selection and screening, adult patients and parents of children with ulcerative colitis will consider fecal bacteriotherapy and are eager for it to become available. These findings have important implications for future microbiome-based treatments.

Keywords

ethical issues in IBD; ulcerative colitis; microbiology of IBD; complementary and alternative medicine; focus groups; fecal bacteriotherapy

Ulcerative colitis (UC) is an idiopathic inflammatory bowel disease (IBD) confined to the rectum and colon. Increasing evidence implicates the intestinal bacterial milieu in the etiopathogenesis of this chronic disease, however, to date there remains no specific organism that is reliably associated with the condition.¹ The Human Microbiome Project (HMP) is a major NIH initiative to explore the human microbiome and support research that explores the interplay between human health and illness, and the organisms that live in or on our bodies.² There has been great interest in this uncharted territory and many challenges face the scientific community in this work. Beyond the scientific questions regarding the role of the microbiome in health and disease lie myriad issues concerning the ethical and social implications of HMP research and microbiome-based therapies.

Interest in microbiome-based therapies is due in part to the fact that currently available medical therapies for ulcerative colitis are often ineffective or carry frightening safety concerns for patients. Despite a number of new therapies for UC, a significant number of patients live with active symptoms and have a poor quality of life.³ As such, patients with ulcerative colitis frequently embrace alternative therapeutic options such as probiotics.⁴⁻⁶

Fecal bacteriotherapy (FB) is an alternative microbiome-based therapy, also known as “human probiotic infusion”, “stool transplant”, “fecal transfer”, or the more recently proposed term, “fecal microbiota transplantation” (FMT). Fecal bacteriotherapy involves collecting stool from healthy pre-screened donors, preparing it, and administering it to an individual with disease. Reports from as early as 1958 suggest that FB is safe and may be effective for a variety of gastrointestinal conditions including inflammatory bowel disease.⁷⁻⁹ Recognizing the immense interest in complementary and naturalistic therapies for ulcerative colitis,⁴⁻⁶ as well as recent work demonstrating the potential of fecal bacteriotherapy,^{9, 10} we undertook a qualitative study to explore the attitudes, interests, and concerns of adult patients and parents of children with UC, regarding fecal bacteriotherapy as a treatment for ulcerative colitis.

PATIENTS AND METHODS

Adult patients with ulcerative colitis and parents of children with UC or indeterminate colitis were recruited from the outpatient adult and pediatric IBD clinics at the University of Chicago Medical Center between November 2009 and January 2010. We conducted six separate focus groups, four for adult UC patients and two for parents of children with colitis between December 2009 and January 2010. Participants received discounted parking and food was provided during the sessions. The focus groups were conducted by an expert qualitative methodologist not associated with the patient care teams (RGB). Clinicians were not present during the focus group sessions as we did not want the participants to be influenced by medical care providers. Focus group sessions were recorded and transcribed. The transcripts were reviewed by the authors independently and then collaboratively to identify domains, themes, and major concepts. The number of focus groups and total number of participants was determined by achieving theme saturation. After we were confident that that this was the case, no further sessions were scheduled. Coding disagreements were resolved by consensus.

A scripted description of fecal bacteriotherapy was prepared by the clinical investigators (SAK and DTR). A focus group Questionnaire Guide (see Appendix) was developed based on the investigators' experiences with the disease (DTR and SAK) and the expertise of a qualitative methodologist (RGB). The participants were asked to discuss their perceptions of, and interest in, fecal bacteriotherapy as a potential treatment for UC. The Questionnaire Guide included questions designed to solicit subjects' impressions, as well as their religious, cultural, and social concerns. It also included questions about: delivery methods, how FB

compares to existing therapies, identification and screening of potential donors, perceived benefits, risks and stigma associated with bacteriotherapy, and factors that would influence their decisions to consider FB. One author (RGB) pilot tested the Guide on a healthy volunteer who is also an independent researcher with extensive experience in questionnaire design. The goals were to 1) pilot test the initial Guide; and 2) to have a mutual brainstorming session among the two expert researchers and use their consensual feedback to improve the Guide on a) the efficiency of sequence of the questions; b) understanding of the questions; and c) length of time required for respondents to answer the questions. The consensus so developed between the two researchers through this process was used to modify the Guide on all three counts stated above, and resulted in an improved and streamlined Guide that was subsequently used to field questions in the Focus Group Sessions. This study was approved by the University of Chicago Institutional Review Board and all participants provided written informed consent.

RESULTS

Demographics

The focus groups included 15 adults with UC (10 men), ages 21–72, and 7 parents of children with colitis (two men), with children ages 8–22. Individuals self-reported their marital status, race, and socio-economic status. The participants represented a range of educational backgrounds, but all had received higher education with at least a bachelor's degree. Disease severity ranged from mild to severe and included four adult patients who had undergone colectomy. Disease duration ranged from 2–35 years in the adults and 1–6 years in the children.

Domains

Our review revealed 5 major domains pertaining to FB: impressions of treatment, benefits, risks, potential mechanisms, and social concerns. From these domains we identified themes and major concepts that were discussed in the focus groups (Table 1). While all of the themes surfaced in the discussions, some of these themes and major concepts dominated the discussions through prolonged and in-depth point and counterpoint views and frequently revisiting a topic. These are the themes that will be discussed below.

Fecal bacteriotherapy as a treatment

All but one subject expressed interest in FB as a treatment for themselves or their child. Parents of children with colitis expressed fewer reservations about FB than adult subjects and some stated that they wished FB was already available (Table 2). FB was consistently compared to probiotics which were uniformly perceived as safe and beneficial. Like probiotics, FB was described as more “natural” and therefore perceived to be safer compared to standard medications (Table 2). When asked which they would prefer FB or probiotics, many subjects felt they were comparable. Most also agreed that FB would be easier and safer than other currently available therapies, especially compared to steroids or biologic agents. “Well if it's less risky than Remicade® [infliximab] then I would say, ‘Hey let's go for it.’”(12/15/09, R2)

Participants spent a great deal of time discussing the logistics of FB including the treatment protocol, duration of effect, and frequency of treatment. However, the most frequently mentioned major concept was the delivery method. Subjects were informed that FB could be delivered by nasogastric tube, enema, or spray colonoscopy. It was uniformly agreed that enema or colonoscopy, would be the preferred delivery method rather than nasogastric tube. There was also general consensus among the participants that FB was analogous to a blood bank system. They also discussed how patients might be matched to their ideal bacterial

donor. “You think there would just be a bank...They would take your sample [and find] that you're missing A, D, and F that this donor has.” (12/15/09, R3)

When asked about what factors they would consider important in their decision to consider FB, participants routinely stated that their willingness would be heavily influenced by their physician's recommendation and their trust in their physician. “If Dr. X [name removed for anonymity] tells me this a more effective treatment I'll take it because I trust my doctor.” (1/15/10, R2) Other important factors included: disease severity and/or the need for surgery, quality of life, and animal and human research that provided supporting data. Relatively few participants mentioned cost and or coverage of the treatment by their insurance company as a major factor in their willingness to consider fecal bacteriotherapy.

Despite their comfort level in discussing their bowel habits and treatments, many participants agreed that branding and naming of the treatment would be important. Some commented that calling it “fecal bacteriotherapy” made sense since it technically described the treatment, some felt that using the word “fecal” was a turn-off, while others stated that as long as it was safe and effective the name did not matter.

Benefits of fecal bacteriotherapy

Despite the lack of strong evidence demonstrating the benefits of fecal bacteriotherapy for UC, many of the participants, particularly those in the parent groups felt that FB would be beneficial. According to one mother, “I think it's a good therapy and I think it will benefit my son.” (1/21/10, R1) Discussions in this domain all related to the theme of effectiveness. Participants asked whether FB would be used to induce or maintain remission. Many speculated and hoped that it would be effective and decrease their medication burden. Some raised the possibility of cure. Most of the major concepts raised in this domain related to the delivery method, with subjects questioning whether the delivery method would impact the effectiveness of the treatment (Table 2).

Risks of fecal bacteriotherapy

Focus group discussions related to risk were dominated by concerns about donors. Donor identification, selection, screening, health, and matching were raised in all of the groups. Regarding the topic of “healthy” donors, participants questioned how “healthy” was defined and discussed the difficulties around such a broad definition. Two major concepts emerged as key donor-related issues: appropriate donor selection and adequate donor screening. Although many patients and parents agreed that they would want a family member to be the donor, many recognized the role of genetics in IBD and questioned whether or not that should be considered in determining appropriate donors.

Participants were asked how FB compares to other human tissue transplants. General consensus was that although FB is often referred to as “stool transplant” it was safer and differed significantly from solid organ transplantation “I would compare it [FB] to a probiotic and not to an organ transplant. I don't think of this as an organ transplant.” (12/10/09, R3)

The single most important theme that emerged in all of the focus groups was donor screening (Table 2). Participants questioned how donor health would be evaluated, the role of the donor's diet and medications, screening for toxins and known diseases Several participants also raised concerns about pathogens or toxins for which we do not currently screen, “Well, I am just interested to note how they're going to prepare this [FB] to give to humans because there are so many things in the colon like parasites and all kinds of by-products.” (12/15/09, R2)

In general we found concordance between the adult patient and parent groups; however, differences emerged during discussions around donor selection and treatment effects. Parents were more concerned with donor selection and being a part of the selection process than adult patients. Adult patients had less specific concerns about who the donor was as long as they were well matched. Most of the parents agreed that they would like to be the donor for their child unless they also had IBD or a serious health problem. Other participants, particularly those in the adult patient group, brought up the possibility of matching donors to patients based on bacterial analysis to ensure that treatment with FB would replace the patient's deficient intestinal bacteria. Both groups emphasized that donor screening was of critical importance. Some discussed the possibility of anonymous donations and the hope that donation would be done altruistically. Although parents of children with colitis perceived FB as safe and natural, several expressed concern about FB leading to worsening of the disease. These concerns were based on their personal experiences and whether or not their child's disease was in remission. Parents who felt their children's current therapy was working were reluctant to change to a new therapy even if it was safe and effective. Both parent and adult focus groups mentioned the risk of infection, risk of an adverse reaction, and risk of worsening disease, but these were less important than risks associated with donors.

Mechanisms of fecal bacteriotherapy

A majority of participants demonstrated a strong interest in, and basic understanding of, disease and treatment mechanisms. After the concept of FB was introduced at the beginning of the focus group sessions, many participants went on to postulate how FB works and the mechanisms as they relate to the underlying causes of IBD (Table 2). Subjects recognized that the “good bacteria” from the donor would “fight” and replace the “bad bacteria” that is in part responsible for IBD. They hypothesized that FB would replace a missing “essential” element in individuals with IBD and that FB would improve the colonic environment for “good bacteria.”

Participants also spent time exchanging views on the causes of IBD cited as: an unknown trigger for the disease, the role of genetics as it related to family members with IBD, the role of infection, bacteria, and antibiotics, and the role of environmental factors. Participants drew from their personal experiences and their perceptions of what caused their or their child's disease. With respect to environmental factors causing IBD, participants, especially those in the parent groups, talked about the importance of diet, relating numerous anecdotes about various diets and foods that they felt contributed to their child's colitis and its improvement.

Social concerns about fecal bacteriotherapy

A majority of the participants expressed initial disgust or distaste for the concept that many referred to as the “yuck factor” (Table 2). The “yuck factor” did not alter participant interest in FB as they agreed that having colitis in and of itself was very unpleasant and had altered their perceptions and willingness to consider unpleasant therapies. “The average person walking down the street who's never dealt with any of the stuff we deal with might be a little more squeamish but I think we've dealt with everything.” (12/15/09, R1) Despite the “yuck factor”, none of the participants expressed concerns about feeling dirty or contaminated by FB. None reported religious or cultural concerns about FB.

Participants noted that there were a number of issues relating to social stigma and acceptability. Adult patients and parents differed with respect to their social concerns. When asked if they would share information about this treatment with friends and family, adult patients said that it would depend. Adult patients who were private about their disease were

unlikely to share information about this treatment. Adult patients who were comfortable sharing health information said they had no specific concerns about sharing information regarding fecal bacteriotherapy. Several adult patients commented that they expected to hear jokes about fecal bacteriotherapy if they told family and friends; however, this would not affect their willingness to accept this therapy. Parents' concerns about acceptability and stigma depended upon: whether or not they felt their child would accept FB, how involved the child was in treatment decisions, the method of delivery, and the age of the child. Most parents agreed that teenagers with colitis played a significant role in their treatment decisions though they as parents try to guide their child's decisions. One parent said that it would be difficult to convince her child to accept the therapy even if it was effective, while another parent said that her child already had friends "lining up" to be donors.

DISCUSSION

In 2003, Borody et al. published a case series of 6 adult patients with moderate to severe medically refractory ulcerative colitis who were treated with fecal bacteriotherapy. After treatment all 6 patients were able to discontinue their conventional therapies and went into long-term clinical remission with documented mucosal healing¹⁰. These findings suggest that fecal microbiota transplantation may be an important treatment for ulcerative colitis. In addition, this study highlights the need for additional studies of FMT not only to evaluate the clinical and microbiological effects, but its social and ethical impact as well. Among its stated goals, the NIH Human Microbiome Project seeks to address "the ethical, legal and social implications raised by human microbiome research."¹¹ Although leaders in the field have highlighted the importance of and the need for research into the ethical and social considerations,^{2, 12, 13} research in this area is limited to date. This is the first study to explore important ethical and social issues surrounding fecal bacteriotherapy or as it is now becoming known, fecal microbiota transplantation, as a treatment for ulcerative colitis.

This qualitative study revealed that both adult patients with UC and parents of children with UC are willing to consider FB as treatment and are eager for it to become available. Our qualitative analysis demonstrated that given adequate supporting research and donor selection and screening, all but one subject was interested in trying FB for themselves or their children, and several wished it were already available. Although initial distaste/disgust and "yuck factor" were uniformly mentioned when discussing FB, these concerns were outweighed by perceived benefits. Participants routinely stated that living with the disease was far worse than any treatment and had changed their tolerance for therapies that others might consider unacceptable or unpleasant. The most important concerns raised in the focus groups were donor selection and donor screening.

Participants felt that FB was comparable to probiotics. Most understood the potential role of bacteria in IBD and why FB may be an effective treatment. Though sufficient data to support FB as a treatment for UC is lacking, they felt it was safe, "natural", and easier than currently available therapies. All reported a preference for colonoscopic or enema delivery, but said that it would depend on which method was the most effective. Most understood the potential role of bacteria in IBD and why FB may be an effective treatment. Given the high rate of complementary and alternative therapy use in patients with IBD, it is not surprising that patients and parents are interested in FB.

The trend toward patient-centered and patient-driven healthcare continues to be a growing force in medicine. Studies have shown that patients, and specifically those with IBD, want considerably more information about their conditions and want to take a more active role in treatment decisions.^{14, 15} There are now a number of website bulletin boards on which there have been active discussions by patients about fecal microbiota transplantation. In our

review, these discussions have almost always been positive, and alarmingly reveal that some patients are now trying this treatment strategy at home without medical supervision.^{16–18} These reviews, coupled with our findings from this study make it is clear that many patients “are ready” for fecal bacteriotherapy.

Recent studies have demonstrated that fecal microbiota transplantation is safe and effective in treating refractory and recurrent *Clostridium difficile*-associated diarrhea.^{19–21} Other groups have shown that FMT alters the host microbiota in a sustained manner that correlates with clearance of the infection.^{22, 23} These studies have significant implications for IBD patients who similarly may benefit from FMT. However, as these investigations move forward the important ethical and social issues must also be addressed. Martin Floch raised this issue in his recent editorial on fecal bacteriotherapy, “...one of the major problems is to define how this therapy can become socially accepted...Nevertheless, replacement of the microflora of an ill person with the microflora from a healthy person holds great promise as a transplant procedure.”¹³

A limitation of this study is that it may not be generalizable to all IBD patient populations. In particular patients with Crohn's disease, that involves the small bowel and upper gastrointestinal tract, may have more questions and concerns about a therapy directed at the colonic microbiota. Though the participants represented a wide range of disease severity, the subjects were recruited from the University of Chicago Medical Center IBD clinics which serve as a referral center for the most complex and severe cases. Patients and parents of children with less severe disease may not be as willing to accept or consider FB. In addition the focus groups only included participants who spoke English and may not represent non-native English speakers or individuals with diverse ethnic backgrounds. All of the participants were highly educated and at a minimum had a Bachelor's degree which may also have had an impact of the discussions. Studies have shown that knowledge and use of complementary and alternative medicine correlates with level of education.^{6, 24}

We report findings from the first study to examine key ethical and social issues regarding fecal bacteriotherapy as a treatment for IBD. Participants perceived FB as “natural” and similar to probiotics. Patients with ulcerative colitis and parents of children with colitis are likely to embrace fecal bacteriotherapy provided that issues of donor selection and safety are addressed. These findings have implications for microbiome research and future microbiome-based treatments. Future studies should not only focus on the scientific and clinical outcomes of fecal bacteriotherapy, but on the important ethical and social issues as well.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Sources of Support: 1. NIH, University of Chicago CTSA K12 Scholars Program UL1 RR024999 (to Dr. Kahn)

2. Gastrointestinal Research Foundation Associates Board Grant (to Dr. Kahn)

References

1. Sartor RB. Microbial Influences in Inflammatory Bowel Diseases. *Gastroenterology*. 2008; 134:577–594. [PubMed: 18242222]
2. Turnbaugh PJ, Ley RE, Hamady M, et al. The human microbiome project. *Nature*. 2007; 449:804–810. [PubMed: 17943116]

3. Rubin DT, Siegel CA, Kane SV, et al. Impact of ulcerative colitis from patients' and physicians' perspectives: Results from the UC: NORMAL survey. *Inflamm Bowel Dis.* 2009; 15:581–588. [PubMed: 19067414]
4. Quattropani C, Ausfeld B, Straumann A, et al. Complementary alternative medicine in patients with inflammatory bowel disease: use and attitudes. *Scand J Gastroenterol.* 2003; 38:277–282. [PubMed: 12737442]
5. Markowitz JE, Mamula P, delRosario JF, et al. Patterns of complementary and alternative medicine use in a population of pediatric patients with inflammatory bowel disease. *Inflamm Bowel Dis.* 2004; 10:599–605. [PubMed: 15472521]
6. Wong AP, Clark AL, Garnett EA, et al. Use of Complementary Medicine in Pediatric Patients With Inflammatory Bowel Disease: Results From a Multicenter Survey. *Journal of Pediatric Gastroenterology and Nutrition.* 2009; 48:55–60. 10.1097/MPG.1090b1013e318169330f. [PubMed: 19172124]
7. Eiseman B, Silen W, Bascom GS, et al. Fecal enema as an adjunct in the treatment of pseudomembranous enterocolitis. *Surgery.* 1958; 44:854–859. [PubMed: 13592638]
8. Bennet JD, Brinkman M. Treatment of ulcerative colitis by implantation of normal colonic flora. *Lancet.* 1989; 1:164. [PubMed: 2563083]
9. Borody TJ, Warren EF, Leis SM, et al. Bacteriotherapy using fecal flora: toying with human motions. *J Clin Gastroenterol.* 2004; 38:475–483. [PubMed: 15220681]
10. Borody TJ, Warren EF, Leis S, et al. Treatment of ulcerative colitis using fecal bacteriotherapy. *J Clin Gastroenterol.* 2003; 37:42–47. [PubMed: 12811208]
11. [Accessed February 9, 2011] Human Microbiome Project: Overview. 2011. Available at: <http://commonfund.nih.gov/hmp/overview.aspx>.
12. McGuire AL, Colgrove J, Whitney SN, et al. Ethical, legal, and social considerations in conducting the Human Microbiome Project. *Genome Res.* 2008; 18:1861–1864. [PubMed: 18971311]
13. Floch MH. Fecal Bacteriotherapy, Fecal Transplant, and the Microbiome. *Journal of Clinical Gastroenterology.* 2010; 44:529–530. 510.1097/MCG.1090b1013e3181e1091d1096e1092. [PubMed: 20601895]
14. Nair K, Dolovich L, Cassels A, et al. What patients want to know about their medications. Focus group study of patient and clinician perspectives. *Can Fam Physician.* 2002; 48:104–110. [PubMed: 11852597]
15. Baars JE, Markus T, Kuipers EJ, et al. Patients' preferences regarding shared decision-making in the treatment of inflammatory bowel disease: results from a patient-empowerment study. *Digestion.* 2010; 81:113–119. [PubMed: 20093836]
16. [Accessed February 9, 2011] Healed of ulcerative colitis within 24 hours: Fecal flora replacement protocol. 2005. Available at: <http://curezone.com/forums/fm.asp?i=57263#i>.
17. [Accessed February 9, 2011] Fecal bacteriotherapy - Human Probiotic Infusion - Ulcerative Colitis. 2009. Available at: <http://www.topix.com/forum/health/colitis/TA5ANBB43CD9AP8NP>.
18. [Accessed February 9, 2011] Fecal Transplant - I took the plunge! PART III. 2009. Available at: <http://www.healingwell.com/community/default.aspx?f=38&m=1662417&p=5>.
19. Aas J, Gessert CE, Bakken JS. Recurrent *Clostridium difficile* Colitis: Case Series Involving 18 Patients Treated with Donor Stool Administered via a Nasogastric Tube. *Clinical Infectious Diseases.* 2003; 36:580–585. [PubMed: 12594638]
20. Silverman MS, Davis I, Pillai DR. Success of self-administered home fecal transplantation for chronic *Clostridium difficile* infection. *Clin Gastroenterol Hepatol.* 2010; 8:471–473. [PubMed: 20117243]
21. Yoon SS, Brandt LJ. Treatment of refractory/recurrent *C. difficile*-associated disease by donated stool transplanted via colonoscopy: a case series of 12 patients. *J Clin Gastroenterol.* 2010; 44:562–566. [PubMed: 20463588]
22. Grehan MJ, Borody TJ, Leis SM, et al. Durable alteration of the colonic microbiota by the administration of donor fecal flora. *J Clin Gastroenterol.* 2010; 44:551–561. [PubMed: 20716985]
23. Khoruts A, Dicksved J, Jansson JK, et al. Changes in the Composition of the Human Fecal Microbiome After Bacteriotherapy for Recurrent *Clostridium difficile*-associated Diarrhea. *Journal*

- of Clinical Gastroenterology. 2010; 44:354–360. 310.1097/MCG.1090b1013e3181c1087e1002. [PubMed: 20048681]
24. Langhorst J, Anthonisen IB, Steder-Neukamm U, et al. Amount of systemic steroid medication is a strong predictor for the use of complementary and alternative medicine in patients with inflammatory bowel disease: results from a German national survey. *Inflamm Bowel Dis*. 2005; 11:287–295. [PubMed: 15735435]

Table 1

Domains, Themes, and Major Concepts

Domain	Theme	Major Concept
FB as a treatment	Perceptions	Safety
		Natural (versus chemical)
	FB versus other treatment	Comparisons to probiotics
		Safety and ease compared to other therapies
	Logistics	Treatment protocol
		Delivery method
		Duration of effect/frequency of treatment
	Willingness to try	Matching of donor and recipient/Banking
		Physician recommended
		Dictated by disease severity/need for surgery
Dictated by quality of life with IBD		
Animal/human research supporting effectiveness		
Risks	Branding	Decreases medication burden
		Cost/insurance coverage
	Donors	Name/marketing
		Donor selection
		Donor screening
	Treatment Effects	Donor matching
		Altruism
		Leads to worsening of disease
		Risk of infection
	Benefits	Effectiveness
Ability to induce/maintain remission		
Decrease medication burden		
Mechanisms	How FB works	Potential of cure
		Missing “essential” element that will be replaced
		Improves colonic environment for “good bacteria”
	Causes of IBD	“Good bacteria fights/replaces “bad bacteria”
		Unknown trigger
		Role of genetics
Social concerns	“Yuck factor”	Role of infection/bacteria
		Environmental factors
	Acceptability	Distaste/disgust of treatment with fecal matter
	Stigma	Disease is much worse than treatment
	Privacy	Concerns about telling friends, family, co-workers
	Disclosure to children	Parents willingness to tell child with IBD about FB
		Willingness to discuss FB treatment with others

Table 2

Domains and representative comments from focus group participants

Interest in Fecal Bacteriotherapy as a Treatment	<p>“Yes even though I'm only on Asacol® and I'm pretty much asymptomatic I would still do it [FB].” (12/10/09, R5)</p> <p>“I wish it [FB] was now and not later. I don't know when they're starting it but I want it now.” (1/21/10, R1)</p> <p>“I think that after this discussion and hearing the different phases everybody is at with their colitis, the sooner the better that I would start these [FB] trials...” (1/12/09, R1)</p>
Fecal bacteriotherapy is safe, natural, and comparable to probiotics	<p>“...I even see this [FB] as a more natural way of treating my disease. If I was given the option of 4 pills that have all these chemical that I don't even understand or this kind of natural thing where bacteria that I'm used to would help it, I would do it.” (12/10/09, R5)</p> <p>“I think this is a more natural way to do things, more like a probiotic thing.” (12/10/09, R6)</p> <p>“It sounds like it [FB] can't be harmful or whatever, like some of these other drugs that seem to have the side effects.” (1/21/10, R4)</p>
Fecal bacteriotherapy delivery methods and effectiveness	<p>“Does it [FB] get all the way up to the area that it needs to get? That's what I would worry about. I know a colonoscopy is invasive but I want it [FB] to be where it needs to be.” (1/21/10, R2)</p> <p>“It's which one is the most effective. I mean the convenience only comes into play if it's the case that they're [the delivery methods] are all equally effective. Otherwise, if you're going to go through this you want the most effective treatment.” (1/15/10, R3)</p>
The importance of a healthy donor and donor screening	<p>“Now tell me, I want to know what you would describe as a 'healthy or normal healthy' human being. You said you were just screening for several things but I know that there are many more other things that's in the colon that needs to be taken care of.” (12/15/09, R2)</p> <p>“I would need a donor; somebody healthy would be the best choice for my son. I wouldn't have any qualms about it [FB] as [long] as I knew that the AIDS and hepatitis and all that was screened.” (1/21/10, R4)</p> <p>“Even if it's your family [donating stool] you want to make sure they're screened.” (1/27/10, R3)</p>
Mechanisms of disease and of fecal bacteriotherapy	<p>“...her body is deficient in certain bacteria and we found a way to transplant that bacteria so that it can populate in her colon...” (1/17/10, R3)</p> <p>“I think now the probiotics are the core of our system and I think they're going to find more diseases besides ulcerative colitis and other things it's all because our bacteria in our stomachs are not right.” (1/21/10, R2)</p>
The Yuck Factor	<p>“...the initial thought is the 'yuck factor' but you know what I'm kinds of at a stage in my colitis where I'm kind of on the last straw before removing my own colon. So I'm at a point where I would try anything...” (12/10/09, R4)</p> <p>“It sounds disgusting but depending on what stage you are at in your illness a patient might be potentially willing to overlook the disgusting nature of this just to get relief from the severeness of the illness.” (1/23/10, R1)</p>