

Sexuality Issues in IBD

by Marla C. Dubinsky

INTRODUCTION

IBD impacts the lives of patients in many different ways. One of the most important measures of this impact can be translated through gaining an understanding of how IBD is affecting the quality-of-life of patients afflicted with these chronic intestinal diseases. Quality-of-life can be an indicator of how well patients are doing and can guide treatment decisions. The three principal areas of quality-of-life are: ability to work, capacity to carry out normal daily activities and sustain healthy relationships. The impact of IBD on relationships and sexual health merits special attention. There is a concerted effort on the part of health professional to keep lines of communication open with patients when it comes to topics of pregnancy and fertility. The psychological impact of IBD on sexuality and the practicalities of managing healthy intimate relationships, however, are rarely explored by health care professionals and their IBD patients. The scope of sexuality and IBD includes the areas of interpersonal relationships, sexual and emotional intimacy, self image and sexual activity. Although this is such an important focus of an IBD patient's quality-of-life, there remain obstacles that limit our ability to fully understand how this disease truly impacts the sexual and relationship health of an IBD patient. These obstacles include a paucity of dedicated literature, under targeted area of scientific investigation, the degree of comfort or lack there of surrounding this topic of con-

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versation, and the personal and private nature of sex and defecation. A publication by Trachter has brought much needed attention to this topic and has sparked interest in exploring new areas of research (1).

The purpose if this article is to provide the clinician the tools with which to open up the lines of communication between IBD patients and their health care professionals and bring these critical issues to the forefront of the management of patients with IBD.

INTERPERSONAL RELATIONSHIPS

Disclosure

IBD patients must understand that relationships under the best of circumstances are complex and many factors, illness or not, may affect the stability of a relationship. It is important to remind patients that relationships are built on a foundation of two people supporting one another. The key however to a successful relationship is effective communication and disclosure of the disease to an understanding partner. Disclosing something about the disease can be very difficult and may even evoke fear, especially fear of the partner's reaction. Perhaps the most important decision is the issue of timing, i.e. at what point in the relationship should disclosure take place. A few important points on disclosure can be shared with patients:

1. Disclosure of disease in a new relationship is very different then sharing with a spouse or when in a committed long term relationship.
2. Trust needs to be established between the partners for disclosure to feel safe.
3. A relationship can often flourish after disclosure.

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4. Patients must first feel comfortable with their disease and with themselves.

5. The attitude a patient has about their own disease will help shape the attitudes of those around them.

6. Non-verbal communication, such as body language and physical cues can speak louder than words.

7. Patients need to shape people's perceptions about how the disease affects them by projecting self confidence and self-awareness.

8. Once a patient has decided to disclose the disease to others, he/she will need a game plan: who to tell, what to tell and how much to tell.

9. A key message is that sharing information about the disease can relieve stress and anxiety related to holding back and dealing with it on their own.

The Partner's Perspective

IBD does not just impact the life of the affected individual. IBD patients must understand that this disease affects both partners. Partners can feel helpless, shut out and can even feel selfish when they express needs that they may have. Patients and their partners have the same or similar emotions or feelings about the disease but they approach it from a different perspective which can sometimes cause conflict. When one partner feels inferior to the other, the balance of the relationship shifts, and it is no longer an equal partnership. Telling a spouse or partner about the disease is necessary to maintain the intimacy and trust formed between partners. It may be helpful to have both partners visit the physician and allow the partner the opportunity to ask questions and gain a better understanding of the disease and how it impacts the relationship. Lack of open communication can promote secrecy and mistrust. The sharing of information will enhance and strengthen the relationship which will be translated to all levels of intimacy.

Body and Sexual Self-Image

It is important for both partners to understand how this disease may affect a patient's perception of body and sexual self-image. These feelings may cause the disease to remain hidden and hamper disclosure and promote secrecy. Defecation is a natural physical function that in IBD patients can be unpredictable. Symptoms

may facilitate feelings of shame and can alter one's self-perception particularly when it comes to both body and sexual self-image (1). Urgency, frequency and fear of incontinence can understandably affect one's self esteem and sexual self confidence. Spending a significant amount of time during the day on a toilet, may not promote a healthy body image or positive feelings regarding one's genitalia. The unpredictability of IBD and the fear of unexpected symptoms may permeate self-esteem and psyche in an insidious manner. Additionally, symptoms themselves may be frightening due to their intensity. For instance, the urgency of having to use a bathroom and "having an accident" in adulthood may significantly impact a sense of psychological and sexual self-confidence.

Due to the disease, patients may experience a loss of formal roles such as the breadwinner for the family. This change of roles can impact one's self esteem and sense of self worth.

Sexual Function and Activity

IBD has both direct (e.g., fatigue, constant diarrhea, abdominal pain) and indirect (e.g., side effects of medication, consequences of surgery) effects on an individual's body image, sexual functioning, and interpersonal relationships. Sexual functioning should be looked at as a marker of quality-of-life and for many patients this is what impacts them the most. Sexuality's importance includes its effect on the ability to have and sustain an intimate healthy relationship. Many IBD patients are young people at an age where they are becoming or are involved in serious relationships and worried that the knowledge of this disease will result in rejection and lack of sexual interest. The impact of IBD on sexuality is apparent given the nature and anatomic location of the disease and the resultant symptoms. Most of the research in the area of sexual functioning has been reported in the surgical literature. However Moody, et al reported that women with IBD had a higher frequency of problems with sexual functioning as compared to those women unaffected by IBD (2). More specifically, 27% of women with IBD were not having intercourse as compared to only four in those unaffected ($P < 0.05$). One of the most reported symptoms was that of dyspareunia independent of disease loca-

tion. Maunder and colleagues demonstrated in 343 IBD patients that both men and women expressed sex-related concerns (3). These concerns however tended to be gender specific with men being more concerned about sexual performance and women more concerned about body image, feeling alone, having children and physical attractiveness ($P < 0.001$). Both men and women were concerned about intimacy and feeling "dirty." Although this appears to be consistent with what is reported in clinical practice, the more important point is that these are common concerns for both men and women who do not have IBD. The bottom line being that most individuals have concerns about themselves as sexual beings. Thus IBD patients must be made aware of the fact that they are not alone and that everyone has these concerns.

It is not just the symptoms of the disease that affect sexual functioning but the treatments regularly prescribed as well. The positive impact of treatment is when patients feel better and their disease is under good control. Their well-being, body image and energy level will improve which in turn may enhance sexual desire and functioning. The potential adverse effects of the common medications used should also be considered. Even the mildest of therapies such as sulfasalazine can be associated with a number of dose related side effects as well as sperm abnormalities. The medication with the most impact on sexuality in the IBD patient is corticosteroids. Steroid associated mood changes can strain relationships while the other esthetic side effects such as acne, weight gain, stretch marks, hirsutism and cushingoid facies have a profound impact on body image and self confidence. Both partners need to respect the effects of the disease itself and the treatments employed on sexual functioning. Patients need to let their body heal and gain the necessary strength to work on improving their relationship.

Surgery and Sexuality

Most of the studies on sexuality after IBD surgery have been conducted on patients undergoing colectomy with ileo-pouch anastomosis (IPAA). The majority of studies have shown that sexual desire in both men and women remains virtually intact after IBD surgery. In fact, a study by Berndtsson, et al demon-

strated that most patients resumed sexual activity soon after surgery and were generally satisfied with their sexual life. The only group that seemed less satisfied were those patients who had an ileostomy which resulted in change in body image and/or fear of dislodging the ileostomy appliance (4,5). Tainen and colleagues confirmed that sexual satisfaction is improved after IPAA, mainly due to improved general health (6). Vaginal dryness can occur in up to 25% of women (7) which can impact sexual functioning as does dyspareunia (8). Fear of incontinence actually improves after IPAA with one study reporting a decrease from 34% to 16% post-operatively in women (6).

The impact of IPAA on fertility is a separate issue. Overall fertility in patients with UC, pre-surgery, has been comparable to that of the general population. However, reports have suggested that fertility may be decreased after IPAA (9, 10). The time to pregnancy in patients with IPAA was significantly increased as compared to pre-IPAA and to a control population. The reason for the significant decrease in fertility is likely due to the potential formation of adhesions and blockage of fallopian tubes associated with pelvic surgery (7). Anti-adhesive gels may reduce post operative adhesions and improve fecundability in women with an IPAA (11)

IBD and Pregnancy

The peak incidence of IBD coincides with the peak age of conception and pregnancy. Fertility success appears to be higher for UC as compared to CD and reduced fertility is typically related to disease activity (12). However, the majority of studies have been conducted in a retrospective manner making it very difficult to generalize. What does appear to be consistent is that fertility is increased in patients in remission or following resection of active disease. In addition, there appears to be a higher voluntary childless rate among IBD patients as compared to the general population (13). The effect of pregnancy on the disease and the effect of the disease on pregnancy are not mutually exclusive. For inactive UC patients who get pregnant the relapse rate appears similar to non-pregnant UC patients (34%) and the risk tends to be highest in the

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Table 1.
Summary: Safety of IBD Medications During Pregnancy

Category B	Category C	Category D	Category X
Loperamide	Ciprofloxacin	Azathioprine†	Methotrexate
Mesalamine	Cyclosporine	6-Mercaptopurine†	Thalidomide
Balsalazide	Diphenoxylate		
Corticosteroids	Olsalazine		
Sulfasalazine	Tacrolimus		
Infliximab			
Metronidazole*			

*Safe for use after first trimester. †Increasing use in pregnancy. Briggs GG, et al. *Drugs in Pregnancy and Lactation* 5th ed. Philadelphia, PA. Lippincott Williams & Wilkins; 1998. *Physician's Desk Reference*®. 57th ed. Montvale, NJ: Thompson PDR; 2003.

Table 2.
Safety of IBD Medications in Breast-Feeding

Safe to Use When Warranted	Limited Data Available	Contraindicated
Oral mesalamine	Azathioprine	Methotrexate
Topical mesalamine	6-Mercaptopurine	Cyclosporine
Sulfasalazine	Infliximab	Metronidazole
Corticosteroids	Tacrolimus	Ciprofloxacin

Physician's Desk Reference®. 57th ed. Montvale, NJ: Thompson PDR; 2003.

first trimester (14). Conversely those UC patients who got pregnant while their disease was active, 45% worsened and approximately one-quarter to one-third improved (15). For those patients with inactive CD the relapse rate is also highest during the first trimester and is approximately 30%. The rule of 3's can be applied to those patients getting pregnant with active CD such that one-third stay the same, one-third get better and one-third worsen (16). The case-controlled study by Porter and Stirrat showed no significant difference in pregnancy outcomes between women with IBD and controls, except for a slightly decreased birth weight and an increase in premature births (17). Some increase in spontaneous abortions in Crohn's disease (OR 1.86) and active first-trimester disease have been reported (18) No difference was seen in the obstetric outcomes

between inactive and active cases, except for the cesarean section rate, which was higher in IBD patients (19). Although IBD, especially Crohn's disease, may decrease fertility, these disorders have no major effect on pregnancy outcomes and should not influence obstetrical management. The goals of treating women during pregnancy include establishing remission before conception, maintaining remission during pregnancy and recognizing the greatest risk to pregnancy is active disease and not IBD therapies. The background general population risk for major congenital abnormalities is 3%. Based on the most recent data, there does not appear to be an increased risk of congenital malformations for the therapies currently employed in IBD.

Tables 1 and 2 summarize the safety of medications during both pregnancy and breastfeeding for IBD patients. Although infliximab is rated as a category B medication, recent evidence suggests that infliximab *does* cross the placenta. However, the implications of fetal exposure on the newborn immune system remains unknown (20). Mothers needs to be made aware of this and the newborn should be followed closely for infection. It has been suggested that these infants undergo testing at 6 months of age to confirm a proper serum humoral response to standard vaccinations (tetanus, hemophilus influenza B and pneumococcal). 6-MP and AZA are being used increasingly in pregnancy. Although most obstetricians would like patients off these medications, it is very important that the patient discuss this with the gastroenterologist given that this medication has kept the patient in remission and facilitated the ability to conceive.

Premature withdrawal of 6-MP may significantly impact the outcome of the pregnancy. It is important to remember that the greatest risk to pregnancy is active disease and not active medicine (21). It is recommended that the patient be seen by a high-risk obstetrician as part of the team to ensure that the IBD

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patient remains well throughout pregnancy and delivers a healthy baby. The patient should pay special attention to nutrition and fetal monitoring to ensure growth. The key message to patients is to establish a stable remission prior to conception and to maintain remission throughout pregnancy.

Questions have been raised as to the mode of delivery for pregnant IBD patients. Large data sets do not exist regarding the safety of vaginal delivery and episiotomy in CD patients. The concern is that CD may complicate surgical sites and produce entero-cutaneous fistulae. There is also a concern over the quality of repair after episiotomy/vaginal tears if the perianal area has extensive or multiple areas of healed fistulae. A study by Brandt, et al (22) demonstrated in a group of women with no pre-existing history of perineal disease who underwent a spontaneous vaginal delivery had at least an 18% rate of developing perineal disease after delivery, and this was highly correlated with episiotomy. Cesarean section is most likely preferable in the face of active disease, though there are no trials or studies that have specifically addressed this issue. It is generally felt that both spontaneous vaginal delivery (SVD) and Cesarean section (C/S) are safe in patients with an IPAA. Vaginal delivery has no negative impact on pouch function. However, C/S rates have been reported to be higher for patients with pouches, possibly because of intrinsic fear of damage to it (23, 24). Episiotomy should be avoided in patients with CD, but not necessarily in those with UC (25,26)

Communicating with Patients

Despite the impact of IBD on sexual functioning, these issues remain silent concerns for most patients. Less than 10% of patients with an ileostomy who needed advice actually broached the topic with their physician or enterostomal therapist (27). This is very typical of clinical practice in all IBD patients. It is unlikely that physicians will hear about these concerns spontaneously unless the health care provider specifically asks if there are any sexual issues. In order to foster a safe and trusting environment, it is the physician who will need to bring up the topic and make the patient feel comfortable about these very personal issues. The key to disclosure is normalizing these concerns for patients.

Physicians need to make sexuality an acceptable subject for them to talk about and let patients know that they are not alone. The disclosure that IBD affects many patients' intimate relationships and sexual activity may provide an opening for further discussion and let the patient be assured that their physician is there for them. In other words, you are letting patients know that you understand these concerns and that you believe that they are important and deserve some attention. The timing of when to open the door is important as well. A trusting relationship between the physician and patient needs to be established first and that typically will come when a patient's disease is improved. Not all physicians are interested or trained to discuss these kinds of issues. However, physicians should be prepared to access local resources including mental health counselors, ostomy therapists, sex therapists and support groups. (www.wecareinibd.com, www.ccfa.org, www.uoa.com, www.aasect.org, www.aamft.org)

CONCLUSION

In order to provide optimal care to IBD patients, physicians must view the patient in a more holistic manner. We must treat the whole patient and consider sexuality as an important concern. Talking about these issues can make an enormous difference to your patients since sexual health is a critical part of the patient's quality-of-life. Just by asking and by listening, gastroenterologists can truly change the lives of the IBD patients they treat. ■

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**Crohn's & Colitis Foundation of America
REQUEST FOR APPLICATIONS
BIOMARKERS OF COLON CANCER IN IBD**

Letter of Intent Deadline: January 14, 2006

Application Submission Deadline: January 14, 2006

Total Award: \$143,000 per year for 2 years

Direct Costs: up to \$130,000

Indirect Costs: Up to 10% (\$13,000) of direct costs

RFA: CCFa continues to seek applications to identify biomarkers for colon cancer in patients with IBD. The proposed studies can focus on the exploration of possible candidate biomarkers to be identified through blood tests, stool tests, or tests on simple biopsies of the rectum (no colonoscopies). Potential groups of biomarkers include antibodies against proteins found in precancerous lesions or early cancers, proteins or DNA from cancerous or pre-cancerous lesions that are shed into the stool, and/or identification of genetic mutations that predispose IBD patients to develop colon cancer. This RFA is limited to human investigation and excludes basic in vitro research or preclinical studies in animal models. Specifically, proposed studies could involve:

- Clinical validation of candidate biomarkers
- Studies to identify candidate biomarkers
- Retrospective longitudinal study to evaluate potential biomarker
- Optimize potential biomarker assay (throughput, reproducibility, etc.)
- Development of innovative imaging tests for pre-cancerous lesions

For all applicants:

- You must be established, independent researchers who hold an MD, PhD or equivalent degree
- The proposed research projects must be relevant to the inflammatory bowel diseases
- You must be employed by a public non-profit, private non-profit, or government institution engaged in health care and/or health-related research
- Eligibility is not restricted by citizenship or geography

*Further information, guidelines and applications
can be found at
www.ccf.org*

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