HHS Public Access

Author manuscript

Inflamm Bowel Dis. Author manuscript; available in PMC 2016 April 01.

Published in final edited form as:

Inflamm Bowel Dis. 2015 April ; 21(4): 923–938. doi:10.1097/MIB.0000000000000257.

Getting Personal: A Review of Sexual Functioning, Body Image, and their Impact on Quality of Life in IBD Patients

Sharon Jedel, PsyD, **Megan M. Hood, PhD**, and **Ali Keshavarzian, MD**

Introduction

Inflammatory Bowel Diseases (IBD), including Crohn's Disease (CD) and Ulcerative Colitis (UC), are chronic relapsing disorders associated with distressing and disabling physical and psychological symptoms. Many patients with IBD consider their quality of life to be impaired,[1–3] and this has been demonstrated among patients who are flaring,[4] as well as those who are in remission and asymptomatic.[5] Disease severity tends to be the most important factor influencing quality of life,[6] as greater impairment is found among patients who are symptomatic.[1,2] In addition to IBD related symptoms and complications, numerous psychological and social factors have also been shown to be highly influential in quality of life.[1,2]

Sexual functioning and body image, which encompass a wide spectrum of physiological, biological and psychosocial issues, are important aspects of psychosocial functioning and can significantly impact quality of life. Impairments in sexual functioning may occur physiologically, such as problems with arousal and orgasm, decreased sexual satisfaction, dyspareunia and reduced lubrication in women and erectile dysfunction, retrograde ejaculation and impotence in men. Psychological difficulties may include decreased interest in, and frequency of, intercourse, reduced sexual satisfaction and relationship issues. Body image is an individual's personal experience of his/her body, including perceptions, beliefs, thoughts, feelings, and actions that pertain to physical appearance.[7] Impairments in sexual functioning and body image have been associated with poorer quality of life and increased psychological concerns such as stress, depression, and anxiety.[8,9]

IBD is typically diagnosed during early adulthood,[10] a particularly important time for sexual functioning and the development of body image. Sexual functioning and body image are considered important aspects of quality of life, particularly for patients with IBD who may experience significant bodily changes due to their disease. The significance of these issues and their association with quality of life is underscored by studies demonstrating that chief among patient concerns is how the disease will affect their sexual functioning and body image.[11–14] Several studies have shown that both male and female patients fear that IBD will reduce their sex drive, interfere with intercourse, compromise their sexual performance, negatively affect intimacy and relationship quality and cause negative feelings about their physical appearance.[3,11–13,15–18] Patients perceive their disease to have an adverse impact

Sharon Jedel, PsyD, Rush University Medical Center, Chicago, Illinois UNITED STATES, Sharon_Jedel@rush.edu.

on their sexual life[19–23] and body image[3,21] and this has been demonstrated in equal rates among patients with UC and CD.[23] Unfortunately, issues related to sexual dysfunction and body image concerns are rarely discussed between IBD patients and their physicians,[20,24,25] despite the importance of these topics to patients and their interest in addressing it with their doctor.[20,26]

Reviews that address sexual health and body image among the IBD population typically do so within a larger, broader context, such as reviews of quality of life among IBD patients[1,27] (for comprehensive reviews, see *Irvine, 2008* [2] and *Sainsbury and Heatley, 2005* [1]), functional outcomes of surgery,[28–30] or issues specific to women with IBD.[31–33] Recent reviews have described the psychosexual impact of IBD among women[34] and men,[35] though associations between these areas and quality of life remain unclear. Given that reduced quality of life is commonly reported among IBD patients and improvement in quality of life is one of the primary therapeutic goals for these patients, a better understanding of the role of sexual functioning and body image in quality of life for patients with IBD is needed. Thus, the aim of this review is to summarize the current literature on sexual function and body image in IBD patients, emphasizing their impact on quality of life in this population.

Search Strategy

An electronic search of the literature was conducted using the PubMed, PsycINFO and Cochrane databases from 1960 through April 2014. Key phrases included: “Ulcerative Colitis/Crohn’s disease/Inflammatory Bowel Disease AND sexual function,” and “Ulcerative Colitis/Crohn’s disease/Inflammatory Bowel Disease AND body image.” References from original studies and reviews were also examined for their relevance.

The search produced a total of 1,284 citations. After duplicates were excluded, we examined the abstracts of each study and included only those with a primary focus on sexual functioning or body image in adults with IBD. Studies of fertility and reproduction were not included, as these topics are beyond the scope of this review. Since the topic of body image is significantly less common in the literature, we were broader in our search criteria and included all studies that addressed body image, even when it was not a major focus of the study.

We identified a total of 56 studies for the present review (See Tables 1 and 2). These studies were conducted from 1990 through April 2014, written in English, and included samples of at least 10 adults with IBD.

RESULTS AND DISCUSSION

1. Prevalence of impaired sexual functioning and body image

Approximately 35–58% of patients report impaired sexual functioning due to their diagnosis of IBD.[3,20,36] In most studies, the frequency of sexual dysfunction is more common in IBD patients than in healthy controls,[19,20,37] although some studies report that the rate is comparable.[17,19] Similarly, around two-thirds of patients report impairments in their body image.[3] These rates are fairly similar by disease type, with 73% of patients with CD and 60% of patients with UC reporting body image concerns in one study.[3] Rates of sexual

impairment and body image concerns may vary based on other factors, such as gender, disease-related factors and surgical history. For example, studies have found that patients with a stoma or ileostomy demonstrate less desire, more problems with orgasmic function, and an adverse impact on their sexual life, compared to those without,[22,26] and that nearly 100% of patients with a stoma report at least some body image concerns.[3]

Impact of *g*ender on prevalence of impairment of sexual functioning and body image—While sexual impairment and body image concerns are common among many patients with IBD, these issues tend to be more prevalent in women than in men.[3,11,20,27,38–43] Women typically report greater problems with desire/libido, sexual satisfaction, decreased frequency of, and lack of interest in, sexual activity, and fecal incontinence during intercourse.[3,20,27,39] Problems with lubrication, dyspareunia and vaginal infections have also been frequently demonstrated in cross-sectional studies of women who have not had surgery,[17,37] as well as post-operatively in those who have had surgery.[17,19,20,37,44] Although women demonstrate greater impairment, there is also evidence of impotence, erectile dysfunction, retrograde ejaculation and reduced sexual interest in men with IBD.[27,39,45–48] Some initial research suggests that men attribute worsening intimacy to psychological disease-related effects such as depression and work-related disability, while women blame disease-related symptoms such as abdominal pain, diarrhea, and incontinence.[20] Interestingly, despite sexual impairment, satisfaction with one's significant other may still be high.[3,44] A study of women with CD and UC found a higher than average level of partnership satisfaction despite the reported low sexual interest among women with CD and UC.[44]

Around three-quarters of women and half of men report impairments in body image.[3] Body image in women tends to be more impacted by IBD surgery than in men. For example, body image scores tend to be higher in patients following laparoscopic versus open procedures and in non-operated versus operated patients, though these differences are typically found only in women.[3,42,43,49] These gender differences may persistent for many years post-surgery, particularly in patients who undergo open surgery.[43] Conversely, some studies have found no differences in body image or ratings of incision scars among men and women post-surgery.[12,50]

These findings suggest that sexual impairment and body image are common among patients with IBD and are important factors that could impact quality of life. Thus, the topics of sexual functioning and body image should be routinely discussed with all IBD patients, especially before surgical intervention.

2. How IBD Impacts Sexual Functioning and Body Image

IBD can affect sexual functioning and body image both directly and indirectly. Factors such as IBD-related symptoms, medications, comorbid illnesses and surgery may play a role. From the perspective of many IBD patients, impairments in sexual functioning are frequently due to specific symptoms, such as abdominal pain, diarrhea, fear of fecal incontinence and fatigue[6,15,16,24,37,51] and can impact how individuals experience and think about their bodies. Fecal incontinence has been shown to be inversely correlated with sexual

satisfaction among patients with and without surgical history,[24] with some patients consequently limiting or altering their sexual activity.[51] It is also possible that non-gastrointestinal IBD symptoms, such as fever, decreased energy, and joint pain due to arthritis, impair sexual functioning, and to a lesser degree body image, although research is lacking in this area.

Role of IBD disease activity—Active disease is associated with impairment in multiple domains of sexual functioning, including decreased intercourse frequency, sexual desire, orgasmic function, erectile function and satisfaction with intercourse.[6,19,36,44] It is noteworthy that high rates of abstinence and low interest in sex (ranging from 19% to 67%) have been noted in both active and inactive patients.[6,17,21,37,44,52–54] High rates of impaired sexual functioning in patients with inactive disease could be due to the fact that several non-GI symptoms like fatigue and joint pain are still common in those with inactive disease. In men, erectile and ejaculatory problems have been correlated with disease activity, with male patients who were in remission or had mild activity reporting similar erectile function as controls.[19] Among women, disease activity contributed to the prediction of decreased thoughts and desire for sexual activity.[44] Issues related to sexual attractiveness and sexual interest have been strongly associated with disease activity in male[36] and female[44] patients, with those who are symptomatic reporting decreased feelings of attractiveness and interest in sexual activity.[36] There are inconsistent data regarding the relationship between disease duration and sexual dysfunction. In one study, longer disease duration was actually protective for multiple domains of sexual functioning among men, even after controlling for age, disease activity, and severity of disease. This finding led the authors to suggest that having IBD for a longer period of time may have resulted in improved patient coping.[36] In contrast, several studies demonstrated a negative impact of IBD duration on libido[3] or satisfaction with intercourse[6]; while other studies found no relationship between disease duration and sexual impairment.[44,55]

Role of medications—Side effects from medications may also interfere with sexual functioning and body image among IBD patients. Use of steroids and biologics have been associated with impairment in multiple domains of sexual functioning.[6,20,44,55] The mechanism of the negative impact of biologics on sexual functioning is not clear and this association could simply be due to the disease severity that resulted in use of biologics. Steroids may result in negative body image and impaired sexual functioning due to side effects such as depression, weight gain, fluid retention, acne, and increased facial hair. Antidepressants, which may be prescribed for depression as well as for co-morbid functional gastrointestinal symptoms such as Irritable Bowel Syndrome (IBS), are commonly used among IBD patients and are also associated with sexual side effects and weight gain.[56] Many patients report a perceived negative impact of their medication on their functioning. In a study of 217 IBD patients (CD=127, UC=85 and Indeterminate Colitis= 5), Muller and colleagues found that close to 40% of the participants felt that their IBD medication had a negative impact on their libido or sexual activity, and approximately 10% of patients reported at least occasionally omitting medications because of perceived negative effects on libido or sexual activity. The type of IBD medication that patients were taking was not reported in this study, thus it is unclear whether specific IBD medications were more likely

to be perceived by IBD patients as negatively influencing sexual functioning.[3] Despite this perception by many patients, in a review of sexual functioning among IBD male patients, the authors conclude that there is no evidence that IBD medications per se cause erectile dysfunction in men.[57] Comprehensive study of the impact of medications commonly prescribed for IBD patients on body image and sexual functioning is needed to fill the gap in our knowledge in order for practicing physicians to properly advise their patients and for scientists to develop interventions to minimize their potential negative impacts.

Role of comorbid conditions—The presence of co-morbid psychiatric or functional gastrointestinal disorders, both of which are associated with sexual impairment,[58,59] could also affect sexual functioning and body image in IBD patients. Compared to controls, higher rates of depression and anxiety have been found among IBD patients.[20,44] Indeed, it has been estimated that the comorbidity of depression and anxiety in IBD patients is between 29%–35% during remission, and as high as 80% for anxiety and 60% for depression during active (flare-up) disease.[60] Studies have consistently demonstrated that depressed mood is strongly associated with impaired sexual functioning in IBD patients,[17,19,20,36,39,44] and has been associated with poorer body image.[39] Studies of female[19,44] and male[19] IBD patients, indicated that IBD patients who were more depressed were more likely to report reduced sexual thoughts or desire, problems with orgasm, reduced satisfaction, reduced intercourse frequency and reduced partner satisfaction.[19,44] In fact, depressed mood was the strongest and most consistent risk factor for low sexual functioning, and more influential than any IBD disease-specific factors that were assessed. Thus, co-morbid depression, which may be related to the experience of having IBD, could be more important than any other IBD-related factor in predicting sexual dysfunction. Future studies should include a specific assessment of depression in order to improve our understanding of its relationship with sexual dysfunction and body image among IBD patients.

Increasing evidence demonstrates that a comorbid diagnosis of IBS is also common among IBD patients.[61,62] High rates (24% to 43%) of sexual dysfunction have been reported among male and female patients with IBS.[58] It is therefore possible that some of the symptoms of sexual dysfunction in IBD patients may be due to IBS-related symptoms rather than to the diagnosis of IBD per se. Yet, we found it surprising that only one study[54] in our review included an assessment of IBS in IBD patients, although there was no separate analysis of sexual dysfunction in patients with IBD and IBS, and thus conclusions could not be drawn regarding the higher incidence of sexual impairment in this subset of patients. This is an area where additional research is necessary.

Role of IBD surgery—Rates of surgery for UC patients depends on disease severity and surgery is extremely rare (less than 5%) in those who do not require steroids and is as high as 50% in those who require IV steroids to treat UC flare-ups and those with prednisone refractory disease.[10,63] Among patients with CD, at least 50% will require at least one surgery at some point in their life.[10,63] Rates of sexual dysfunction and problems with body image tend to be worse in those who have had IBD surgeries compared to those who have not had surgery.[3] This increased rate could be due to the more severe nature of the symptoms of those requiring surgery or the impact of the surgery on the body and bodily

functioning[3]. However, several studies demonstrated that both male and female IBD patients often report improvements in multiple domains of sexual functioning post-operatively regardless of the type of surgical procedures. This improvement is most likely due to the fact that surgery can induce remission, treat IBD complications like abscesses, fistulas, and perianal disease and thus improve IBD-related symptoms associated with active disease. For example, improvement of sexual functioning has been reported following Ileo Anal Pouch Anastomosis (IPAA),[16,22,47,64,65] mesorectal and rectal excision,[27,66] and restorative proctocolectomy.[22] The improvement of sexual functioning after surgery has not been shown in all studies. For example, some studies report no changes post-operatively in 51% to 80% of male and female study samples in numerous domains of sexual functioning, including desire, arousal, lubrication, orgasm, satisfaction, pain and intercourse frequency.[16,47,51] Indeed, other studies have found even *increased* post-operative levels of sexual impairment among women, including increased dyspareunia,[15,16,51] decreased libido,[15] and problems with lubrication.[15,26] In fact dyspareunia is commonly reported among patients following IPAA,[16,38,46,49,53,67] with rates as high as 30%.[46] However, the majority of these studies did not include preoperative assessments of sexual functioning, making it difficult to interpret results of post-operative sexual functioning. Many were conducted at least one year after the surgery, when patients' recollection of symptoms may be different compared to soon after surgery.[6,15,21,46,47,54,67]

Among men, most studies indicated that ejaculatory dysfunction and impotence were not common following IPAA in UC patients[38,49,64,65,67] or surgery for anal fistulas in CD patients.[6] However, one study reported impotence or retrograde ejaculation in 26%[46] of patients following IPAA, and erectile dysfunction in 5% of men following total mesorectal excision.[27] Surprisingly, no significant differences in multiple domains of sexual functioning have been detected between patients with healed versus unhealed fistulas in patients who had surgery for rectovaginal[54] or anal fistulae;[6] between patients with a functioning versus failed pouch;[53] between women who had restorative proctocolectomy versus those who did not have a stoma or restorative proctocolectomy;[52] or between adult patients who had restorative proctocolectomy in childhood and adult patients with no prior surgery.[24] Nonetheless, it appears that when extensive pelvic dissection is part of the surgical procedure, the frequency of sexual dysfunction is higher, especially among men, compared to those who did not have extensive pelvic dissection.[48]

As noted above, the majority of studies exploring IBD surgeries and sexual functioning assessed post-operative results *only* and therefore it is unclear whether post-operative reports of sexual dysfunction are indicative of deterioration or improvement in sexual functioning. The lack of pre-operative assessment may help explain the discrepancy in results of surgical studies. Interestingly, data from three studies following proctocolectomy and IPAA that did include pre-operative assessments demonstrated high baseline scores on measures of sexual functioning among both male and female patients.[22,64,65] These studies reported statistically significant improvements in many domains of sexual functioning after surgery for men and women.[64,65]

The impact of surgery on body image depends on the type of IBD surgery that is performed. For example, surgical incision scars after laparatomy, and the presence of a stoma may

negatively impact body image.[40] The introduction of laparoscopic and pouch-forming techniques has minimized surgical scars and eliminated the protruding stoma and need for external appliances for many patients[68] and thus could minimize the negative impact of IBD surgeries on body image. Though body image and cosmesis are unconventional outcomes in the general surgery field (outside of cosmetic surgery), the importance of these outcomes is highlighted by the fact that some authors suggest that, particularly for women, the potential long-lasting positive effects of the laparoscopic and pouch-forming procedures on body image and cosmesis outweighs the higher costs and longer operative times of these procedures.[43] Studies consistently indicate that satisfaction with the surgical scar is better after laparoscopic versus conventional open surgeries[12,43,50,69] and tends to be moderately to strongly correlated with body image.[38,41] While a number of studies have shown better post-surgical body image for laparoscopic versus open procedures,[12,41,43,69,70] some have found no differences in body image between these groups.[38,49,50,67] As noted above, some studies have found that these differences in body image by surgery type occur in women only. Patients with a stoma tend to have poorer body image than those who receive pouches,[71,72] and patients who have undergone surgery tend to have more body image concerns than those who have not had surgery.[3] The number of stages (1- versus 2-stage procedures) for IPAA surgery does not appear to impact body image.[12,38]

Understanding the frequency and severity of sexual dysfunction and body image concerns is important since there are therapeutic modalities that can improve and treat these concerns, minimizing the negative impact on patient quality of life. For example, results from a double-blind, placebo-controlled trial of Viagra for erectile dysfunction after rectal excision demonstrated significant improvement among male IBD patients.[66] Thus, we believe that formal measurement and assessment of sexual functioning and body image and their impact on patients' quality of life should be incorporated in physicians' overall assessment of patients with IBD.

3. Measurement of Sexual Functioning, Body Image, and Quality of Life in IBD

The constructs of sexual functioning, body image and quality of life are assessed with various measures, most often standardized self-report questionnaires or questionnaires that are developed by the study investigators.

Sexual functioning—Sexual functioning is most commonly measured by the International Index of Erectile Function for men (IIEF)[73] and the Female Sexual Function Index (FSFI)[74] for women. These measures have been used in over 4,000 studies and translated into numerous languages. The IIEF is a 15-item questionnaire that assesses the following domains of male sexual functioning: erectile function, orgasmic function, sexual desire, intercourse satisfaction and overall satisfaction. The IIEF has demonstrated good internal consistency (Cronbach's alphas for the five domains ranging from .73 to .92 with an overall alpha of .91), test-retest reliability and discriminant validity by capacity to distinguish between patients with erectile dysfunction from age matched controls. Higher scores indicate better sexual function. The FSFI is a 19-item questionnaire that measures the following domains: desire, subjective arousal, lubrication, orgasm, satisfaction and pain. The FSFI also demonstrates good internal consistency (Cronbach's alpha values of 0.82 and

higher), high test-retest reliability and divergent validity with a marital satisfaction scale. Higher scores indicate better sexual function.

The Sexual Function Questionnaire (SFQ)[75] is a 34-item questionnaire that has been validated among women and measures the domains of desire, enjoyment, sensation, lubrication, pain and orgasm. This measure has not been commonly used in studies of IBD patients.

The Sexual Problems Scale (SPS)[76] is a brief, 4-item questionnaire assessing perceived impairment in sexual arousal and orgasm. One question is gender specific and inquires about difficulty achieving erection (for men) and reaching orgasm (for women). Higher scores indicate greater levels of perceived sexual problems. This measure is also infrequently administered to IBD patients.

Many studies in this review,[3,16,17,22,24,27,46,47,55,67] used self-created questions to assess sexual functioning among or modified versions of other questionnaires with similar content.[21,37,39,51] These questionnaires assessed many of the same domains as the standardized measures above. Some also included questions pertaining to the patient's relationship with his/her significant other.[3,17,37]

Body Image—The most commonly used research measure of body image in patients with IBD is the Body Image Questionnaire (BIQ).[41] This 8-item self-report measure evaluates body image after surgery. Results of a factor analysis revealed two factors: body image and cosmesis. The body image subscale assesses the patient's perception of and satisfaction with the body as well as attitudes about bodily appearance. The cosmesis subscale assesses the degree to which the patient is satisfied with the physical appearance of his/her scar. The BIQ has been shown to have adequate reliability (Cronbach's alphas of .80 to .83).[41]

McDermott et al.[42] recently published the Body Image Scale, a 9-item single-factor scale specifically designed to assess body image in patients with IBD. The scale was modified from a body image scale created by Hopwood et al.[77] for patients with cancer. The scale has demonstrated good internal consistency (Cronbach's alpha = 0.93), test-retest reliability, convergent validity with a well-known body image questionnaire, and predictive utility.[42] It has been used to a limited degree with IBD patients since its publication in 2014, but shows promise for measuring disease-specific body image concerns in this population.

The Photoseries Questionnaire (PSQ)[41] has also been used with IBD patients to determine their degree of satisfaction with their scar and to assess whether satisfaction ratings would vary based on seeing the cosmetic results of a different procedure.

Other studies used self-created questions to assess body image[71] or included body image on a list of potential patient concerns. [3,13,78] Interestingly, some studies have included questions about body image on quality of life questionnaires. For example, Knowles et al.[39] used the Stoma Quality of Life questionnaire (SQOL),[79] which includes sexuality/body image as one of five dimensions of quality of life that are assessed. Mahadev et al.[80] created a quality of life questionnaire to assess functioning in 16 areas relevant to patients with

perianal CD, including “self-image” and “cosmetic appearance” items, which formed the cosmetic subscale.

4. Impact of Sexual Functioning and Body Image on Quality of Life in IBD patients

Measurement of quality of life—Studies included in this review used a variety of self-report measures to assess quality of life among IBD patients. General health-related quality of life was most commonly measured using the Short Form Health Survey-36 (SF-36) or its abbreviated versions (SF-8 and SF-12).[81] Disease-specific quality of life was measured using the Inflammatory Bowel Disease Questionnaire (IBDQ)[82] or its shortened version, the SIBDQ,[83] the Gastrointestinal Quality of Life Index (GIQLI),[84] the Cleveland Global Quality of Life scale (CGQL)[85] the Stoma Quality of Life Scale (SQOL)[79] and the Fecal Incontinence Quality of Life Scale (FIQL).[86] The Rating Form of IBD Patient Concerns (FIPC) [87] was also used as a measure of quality of life in some studies. In addition, some authors created their own quality of life questionnaires for their studies.[3,13,45,80,88]

Sexual functioning and quality of life in IBD—Our review identified 14 studies that measure sexual functioning and quality of life among IBD patients (See Table 1), of which 13 were related to a specific surgery. Most studies demonstrated significant improvements in measures of quality of life following colectomy with IPAA,[46,64,65] mesorectal excision[27] and pelvic or abdominal colorectal surgery,[26] although only two[64,65] included pre-operative assessments. When patients undergoing open IPAA were compared to patients undergoing laparoscopic IPAA, no significant differences in quality of life scores were found between the groups,[49,67] although interestingly, quality of life scores were within normal range in one of these studies[67] whereas some impairments in quality of life were found in the other.[49]

As expected, patients with more severe disease and post–operative complications typically demonstrate more impaired quality of life. For example, in a study[52] that compared females with UC and prior restorative proctocolectomy (n=53) to females with UC who did not have a stoma or restorative proctocolectomy (n=47), quality of life, as measured by the SF-36, for overall physical health (p=0.020) and bodily pain (p= 0.042) were significantly better among UC patients without surgery. No significant differences were found between the groups in sexual functioning, as measured by the FSFI. However, the median FSFI score of patients with restorative proctocolectomy was indicative of sexual dysfunction[52]. Likewise, a study[6] of 69 patients with CD having surgery for anal fistulas showed that the type of surgery and severity of symptoms impact IBD-Q scores. Results from a univariate analysis indicated that type of operation (fistulotomy better than loose seton drainage, p=0.03), type of fistula (simple better than complex fistula, p=0.004), current complaints due to Crohn’s Disease (active disease greater than inactive, p< 0.0001), and current perianal complaints (p=0.015) significantly impacted quality of life. Quality of life was also significantly altered (p=0.0006) in male and female patients with fecal incontinence.[6] No significant differences on the IIEF and FSFI were found between the groups. Median scores on the FSFI were indicative of sexual dysfunction for both female patients and controls, and patients scored lower.[6] Finally, when UC patients with a failed pouch (n=36) were compared to those with a functioning pouch (n=72), participants with pouch failure scored lower on all quality of life domains, although only the social function domain for men was statistically significant. No

significant differences were found between the groups on the FFSI and IIEF. Consistent with results from the studies above, patients with pelvic pouch failure scored lower on these measures compared to controls, and median summary scores for women with pouch failure were indicative of sexual dysfunction.[53] Importantly, not all patients with more severe disease demonstrate greater impairments in quality of life. El-Gazzaz and colleagues examined women with Crohn's-related rectovaginal fistulae. Data from quality of life measures indicated no significant differences between SF-12, IBDQ or FIQL scores between women with healed (n=15) and unhealed (n=14) rectovaginal fistulae. Of the sexually active women (57% of sample), there were no significant differences between healed and unhealed patients in any domains of the FSFI.[54]

As noted, we identified only one study[3] that was not specific to surgery that measured sexual functioning and quality of life in IBD patients, although these constructs were not correlated. Muller et al. asked 217 participants whether IBD had ever affected their quality of life. Nearly 89% of the cohort reported a negative impact on quality of life and there were no significant differences between genders, disease types or those who had been operated on and those who had not. In this study, a greater proportion of women (66.3%, versus men: 40.5%, p< 0.0001) reported decreased frequency of sexual activity, as did participants with prior surgery (68.5%) compared to those with no surgical history (52.6%, p=0.0113). Women (67.1% versus men: 41.9%, p=0.0005) and subjects with prior surgery (67.4% versus 52.6% with no prior surgery, p=0.035) reported significantly more decreased libido. There was also a significantly greater rate of perceived negative impact on relationship status among patients with prior surgery (64%) compared to those with no prior surgery (41%, p=0.0014).[3]

Of the 14 studies that included measures of quality of life and sexual functioning, only four examined the correlation between these constructs. A recent Japanese study[55] evaluated sexual activity and quality of life 6 months post-operatively among UC patients (n=61) who had had restorative proctocolectomy with ileal J-pouch anal anastomosis (IPAA). Quality of life was measured by the IBDQ. Scores on the four IBDQ subscales were positively correlated with scores on the sex-specific question of the IBDQ[82] ("To what extent has your bowel problem limited sexual activity during the last 2 weeks?"). Scores for Social functions other than sex life were significantly positively correlated with Sex life score (p= 0.03); scores from the other three subscales were not correlated with Sex life scores. Approximately 31% of patients were classified as having poor sexual activity. When patients with poor sexual activity were compared to patients with good sexual activity, there was a significant difference in scores on the Social functions other than sex subscale (p=0.016), with patients in the poor sexual activity group experiencing more difficulty with social functions. There were no significant differences between these groups on the Bowel, Systemic or Emotional subscales of the IBDQ.

Another study[27] examined sexual dysfunction and quality of life after total mesorectal excision among patients with UC (n=65) and familial adenomatous polyposis (FAP; n=10). Following their surgery (mean follow-up was 33 ± 18.3 months), patients were asked to recall their pre- and post-operative quality of life, rated between 0 and 10. Patients with UC demonstrated significant improvement in quality of life (p<.001), and no significant

differences were found between men and women. Further, among women, approximately 42% reported incidental dyspareunia, 27.8% reported reduced vaginal lubrication and 27.8% reported fecal incontinence during intercourse. Interestingly, when the women with these sexual impairments were compared to those who did not report these symptoms, there were no significant differences in quality of life scores. Moreover, two men reported permanent retrograde ejaculation and although neither of them was sexually active, only one of them reported a decrease in quality of life.

A third study[38] assessed quality of life and sexual functioning, as well as body image, in 26 patients with UC (n=16) or FAP (n=10) aged > 18 years old who had undergone restorative proctocolectomy with IPAA between the ages of 10 to 24. Health-related quality of life was measured using the Dutch version of the Short Form-36 Health Survey[89] and disease-specific quality of life was measured using the Gastrointestinal Quality of Life Index (GIQLI).[84] Ten male and 13 female patients provided complete responses to measures of sexual functioning. While none of the men had scores indicative of sexual dysfunction, 50% of the women did. Interestingly, male and female sexual function were highly correlated (r=0. 70) with quality of life [Physical Component Summary (PCS) and Mental Component Summary (MCS) of SF-36] and GIQLI total scores although the correlation only trended toward significance (p=0.08) in this small sample.

Finally, da Silva and colleagues[26] assessed the effect of abdominal and pelvic surgery on female sexual function. Assessments of sexual functioning and quality of life (measured by the SF-36) occurred preoperatively and at 6 and 12-month follow-up. Ninety-three women, of which 57 underwent pelvic surgery and 36 underwent abdominal surgery, participated. The majority of women (84% in the pelvic group, and 81% in the abdominal group) had benign disease, presumably IBD. Scores from the MCS improved over time, with significant improvement (p= 0.007) demonstrated at 12 months. Scores from the PCS demonstrated significant improvement at 6-months (but no significant improvement between 6 and 12 months. Better sexual functioning was also observed among women with higher MCS and PCS scores (at 6 months).

In summary, the findings from these 4 studies support the idea that there is a positive association between sexual functioning and quality of life among patients with IBD. Additional studies are necessary to more fully understand the relationship between these constructs.

Quality of life and body image in IBD—Of the 25 studies that assessed body image and quality of life found in this review (see Table 2), the association between these constructs was tested directly in only three studies[38,39,41] and, of note, this association was a secondary analysis in all three studies. Dunker et al.[41] administered the Body Image Questionnaire[41] and the Dutch version of the Inflammatory Bowel Disease Questionnaire to 34 patients with CD who had undergone open ileocolic resection (n=11), laparoscopic-assisted resection (n=11) or no resection (n=12). They found that in the overall sample body image scores were significantly correlated with quality of life scores (r=0.50, p=0.02). Body image was also positively correlated with satisfaction with the surgical scar and higher self-confidence in this study.

As described above, Van Balkom and colleagues[38] assessed quality of life and body image in 23 patients with UC or FAP who had undergone restorative proctocolectomy with ileal pouch-anal anastomosis. In this study, body image was measured using the Body Image Questionnaire[41]. A large positive correlation (r=.41) was found between body image and at least one measure of quality of life (details of which measure were not reported), though this was non-significant in this small sample.

Finally, Knowles et al.[39] assessed health-related quality of life using the Stoma Quality of Life Scale (SQOL)[79] in 31 patients with CD who had an ostomy. As noted above, the SQOL includes a 5-item sexuality/body image subscale and in this study this subscale was significantly correlated with two other SQOL subscales: work/social (r=.59, p<.01) and stoma function (r=.49, p<.01). Sexuality/body image was non-significantly correlated with the financial concerns (r=.17, p>.05) and skin irritation (r=.19, p>.05) subscales of the SQOL. Results from these few studies preliminarily suggest a positive relationship between body image and quality of life postoperatively in patients with IBD. Future studies are needed to more fully understand this association given the small number of studies that were found.

5. LIMITATIONS AND FUTURE DIRECTIONS

Several studies included in this review had a number of limitations, including lack of control groups, small sample sizes, low response rates, self-reported data regarding disease and surgical history, use of non-standardized, non-validated instruments to assess sexual functioning/body image and lack of pre-operative assessments of sexual functioning/body image when the impact of surgery on sexual functioning and body image was reported.. Moreover, the studies were frequently cross-sectional, addressing sexual functioning and body image at one time point only. Certainly, physiological (e.g., menstruation, weight gain) and psychological factors (e.g., relationship issues and life stressors) contribute to variations in an individual's sexual desire, satisfaction and frequency of sexual activity, and body image, thereby necessitating the need for assessments over multiple periods of time. These limitations could, at least in part, explain some of the conflicting results in regards to frequency and severity of sexual functioning and body image impairment and their impact on quality of life in patients with IBD. Future studies that address limitations of some of these studies could help clarify some areas in which mixed results were found.

Data regarding quality of life, sexual functioning and body image among IBD patients with no surgical history is extremely limited, and thus we cannot reach a firm conclusion regarding the impact of impaired sexual functioning and body image on quality of life in patients with IBD who have not undergone surgery. This gap in our knowledge is important to address in future studies, particularly given the high rates of depression and anxiety among IBD patients [20,44,60] (particularly in those with active, symptomatic disease[60]) and the association of depression with impaired sexual functioning,[17,19,20,36,39,44] and poorer body image.[39] Moreover, patients who are symptomatic have typically not had surgery. Future studies comprised of patients who have not had surgery are necessary in order to better understand the relationship between sexual functioning, body image and quality of life in patients with active (flare-ups) and inactive (remission) IBD.

Finally, sexual functioning and body image are also influenced by the patient's spouse/significant other. None of the study samples in this review included the patients' partners, and this also represents a limitation in the measurement of these constructs. Insofar as sexual functioning and body image encompass a wide spectrum of physiological, biological and psychological processes, and are impacted by dynamics within the relationship, we believe that the psychosocial functioning of the patient's partner should also be assessed. We recommend that future studies include a more comprehensive assessment of sexual functioning and body image, by incorporating the patient's spouse, in hopes of expanding our understanding of these complex constructs.

Acknowledgments

Support for the current paper was provided by a grant [*Biological & Psychological Factors as Predictors & Indicators of MBSR Responses* (R01AT007143-02)], from the National Center for Complementary Alternative Medicine (NCCAM) of the National Institutes of Health (NIH).

References

1. Sainsbury A, Heatley RV. Review article: psychosocial factors in the quality of life of patients with inflammatory bowel disease. Aliment Pharmacol Ther. 2005; 21:499–508. [PubMed: 15740531]
2. Irvine EJ. Quality of life of patients with ulcerative colitis: past, present, and future. Inflamm Bowel Dis. 2008; 14:554–565. [PubMed: 17973299]
3. Muller KR, Prosser R, Bampton P, et al. Female gender and surgery impair relationships, body image, and sexuality in inflammatory bowel disease: patient perceptions. Inflamm Bowel Dis. 2010; 16:657–663. [PubMed: 19714755]
4. Janke KH, Klump B, Gregor M, et al. Determinants of life satisfaction in inflammatory bowel disease. Inflamm Bowel Dis. 2005; 11:272–286. [PubMed: 15735434]
5. Verma S, Tsai HH, Giaffer MH. Does better disease-related education improve quality of life? A survey of IBD patients. Dig Dis Sci. 2001; 46:865–869. [PubMed: 11330426]
6. Riss S, Schwameis K, Mittlbock M, et al. Sexual function and quality of life after surgical treatment for anal fistulas in Crohn's disease. Tech Coloproctol. 2013; 17:89–94. [PubMed: 22956209]
7. Cash, T. The Body Image Workbook. 2. Oakland, CA: New Harbinger Productions; 2008.
8. Cash TF, Fleming EC. The impact of body image experiences: development of the body image quality of life inventory. Int J Eat Disord. 2002; 31:455–460. [PubMed: 11948650]
9. Lutfey KE, Link CL, Rosen RC, et al. Prevalence and correlates of sexual activity and function in women: results from the Boston Area Community Health (BACH) Survey. Arch Sex Behav. 2009; 38:514–527. [PubMed: 18188686]
10. Keighley MR, Stockbrugger RW. Inflammatory bowel disease. Aliment Pharmacol Ther. 2003; 18(Suppl 3):66–70. [PubMed: 14531744]
11. Maunder R, Toner B, de Rooy E, et al. Influence of sex and disease on illness-related concerns in inflammatory bowel disease. Can J Gastroenterol. 1999; 13:728–732. [PubMed: 10633825]
12. Dunker MS, Bemelman WA, Slors JF, et al. Functional outcome, quality of life, body image, and cosmesis in patients after laparoscopic-assisted and conventional restorative proctocolectomy: a comparative study. Dis Colon Rectum. 2001; 44:1800–1807. [PubMed: 11742165]
13. Carlsson E, Bosaeus I, Nordgren S. What concerns subjects with inflammatory bowel disease and an ileostomy? Scand J Gastroenterol. 2003; 38:978–984. [PubMed: 14531536]
14. Casati J, Toner BB, de Rooy EC, et al. Concerns of patients with inflammatory bowel disease: a review of emerging themes. Dig Dis Sci. 2000; 45:26–31. [PubMed: 10695609]
15. Ogilvie JW Jr, Goetz L, Baxter NN, et al. Female sexual dysfunction after ileal pouch-anal anastomosis. Br J Surg. 2008; 95:887–892. [PubMed: 18551505]
16. Tiainen J, Matikainen M, Hiltunen KM. Ileal J-pouch--anal anastomosis, sexual dysfunction, and fertility. Scand J Gastroenterol. 1999; 34:185–188. [PubMed: 10192198]

17. Moody GA, Mayberry JF. Perceived sexual dysfunction amongst patients with inflammatory bowel disease. Digestion. 1993; 54:256–260. [PubMed: 8243839]
18. Maunder RG, de Rooy EC, Toner BB, et al. Health-related concerns of people who receive psychological support for inflammatory bowel disease. Can J Gastroenterol. 1997; 11:681–685. [PubMed: 9459048]
19. Timmer A, Bauer A, Dignass A, et al. Sexual function in persons with inflammatory bowel disease: a survey with matched controls. Clin Gastroenterol Hepatol. 2007; 5:87–94. [PubMed: 17234557]
20. Marin L, Manosa M, Garcia-Planella E, et al. Sexual function and patients' perceptions in inflammatory bowel disease: a case-control survey. J Gastroenterol. 2013; 48:713–720. [PubMed: 23124604]
21. Sjogren B, Poppen B. Sexual life in women after colectomy-proctomucosectomy with S-pouch. Acta Obstet Gynecol Scand. 1995; 74:51–55. [PubMed: 7856433]
22. Berndtsson I, Oresland T, Hulten L. Sexuality in patients with ulcerative colitis before and after restorative proctocolectomy: a prospective study. Scand J Gastroenterol. 2004; 39:374–379. [PubMed: 15125470]
23. Bokemeyer B, Hardt J, Huppe D, et al. Clinical status, psychosocial impairments, medical treatment and health care costs for patients with inflammatory bowel disease (IBD) in Germany: an online IBD registry. J Crohns Colitis. 2013; 7:355–368. [PubMed: 22503168]
24. Koivusalo A, Pakarinen MP, Natunen J, et al. Sexual functions in adulthood after restorative proctocolectomy for paediatric onset ulcerative colitis. Pediatr Surg Int. 2009; 25:881–884. [PubMed: 19669154]
25. Borum ML, Igiehon E, Shafa S. Physicians may inadequately address sexuality in women with inflammatory bowel disease. Inflamm Bowel Dis. 2010; 16:181. [PubMed: 19408323]
26. da Silva GM, Hull T, Roberts PL, et al. The effect of colorectal surgery in female sexual function, body image, self-esteem and general health: a prospective study. Ann Surg. 2008; 248:266–272. [PubMed: 18650637]
27. Slors FJ, van Zuijlen PP, van Dijk GJ. Sexual and bladder dysfunction after total mesorectal excision for benign diseases. Scand J Gastroenterol Suppl. 2000; (232):48–51. [PubMed: 11232492]
28. Lichtenstein GR, Cohen R, Yamashita B, et al. Quality of life after proctocolectomy with ileoanal anastomosis for patients with ulcerative colitis. J Clin Gastroenterol. 2006; 40:669–677. [PubMed: 16940876]
29. Wax JR, Pinette MG, Cartin A, et al. Female reproductive health after ileal pouch anal anastomosis for ulcerative colitis. Obstet Gynecol Surv. 2003; 58:270–274. [PubMed: 12665707]
30. Izanec J, Nagle D. Impact of proctectomy on continence and sexual function in women. Am J Gastroenterol. 2006; 101:S618–24. [PubMed: 17177865]
31. Okoro NI, Kane SV. Gender-related issues in the female inflammatory bowel disease patient. Expert Rev Gastroenterol Hepatol. 2009; 3:145–154. [PubMed: 19351285]
32. Moleski SM, Choudhary C. Special considerations for women with IBD. Gastroenterol Clin North Am. 2011; 40:387–98. viii–ix. [PubMed: 21601786]
33. Reddy SI, Wolf JL. Management issues in women with inflammatory bowel disease. J Am Osteopath Assoc. 2001; 101:S17–23. [PubMed: 11794750]
34. Trachter AB, Rogers AI, Leiblum SR. Inflammatory bowel disease in women: impact on relationship and sexual health. Inflamm Bowel Dis. 2002; 8:413–421. [PubMed: 12454617]
35. O'Toole A, Winter D, Friedman S. Review article: the psychosexual impact of inflammatory bowel disease in male patients. Aliment Pharmacol Ther. 2014; 39:1085–1094. [PubMed: 24654697]
36. Timmer A, Bauer A, Kemptner D, et al. Determinants of male sexual function in inflammatory bowel disease: a survey-based cross-sectional analysis in 280 men. Inflamm Bowel Dis. 2007; 13:1236–1243. [PubMed: 17508419]
37. Moody G, Probert CS, Srivastava EM, et al. Sexual dysfunction amongst women with Crohn's disease: a hidden problem. Digestion. 1992; 52:179–183. [PubMed: 1459352]

38. van Balkom KA, Beld MP, Visschers RG, et al. Long-term results after restorative proctocolectomy with ileal pouch-anal anastomosis at a young age. Dis Colon Rectum. 2012; 55:939–947. [PubMed: 22874600]
39. Knowles SR, Gass C, Macrae F. Illness perceptions in IBD influence psychological status, sexual health and satisfaction, body image and relational functioning: A preliminary exploration using Structural Equation Modeling. J Crohns Colitis. 2013; 7:e344–50. [PubMed: 23453888]
40. Allison M, Lindsay J, Gould D, et al. Surgery in young adults with Inflammatory Bowel Disease: a narrative account. Int J Nurs Stud. 2013; 50:1566–1575. [PubMed: 23684395]
41. Dunker MS, Stiggelbout AM, van Hogezand RA, et al. Cosmesis and body image after laparoscopic-assisted and open ileocolic resection for Crohn's disease. Surg Endosc. 1998; 12:1334–1340. [PubMed: 9788857]
42. McDermott E, Moloney J, Rafter N, et al. The body image scale: a simple and valid tool for assessing body image dissatisfaction in inflammatory bowel disease. Inflamm Bowel Dis. 2014; 20:286–290. [PubMed: 24374873]
43. Polle SW, Bemelman WA. Surgery insight: minimally invasive surgery for IBD. Nat Clin Pract Gastroenterol Hepatol. 2007; 4:324–335. [PubMed: 17541446]
44. Timmer A, Kemptner D, Bauer A, et al. Determinants of female sexual function in inflammatory bowel disease: a survey based cross-sectional analysis. BMC Gastroenterol. 2008; 8:45-230X-8-45. [PubMed: 18834529]
45. Gorgun E, Remzi FH, Montague DK, et al. Male sexual function improves after ileal pouch anal anastomosis. Colorectal Dis. 2005; 7:545–550. [PubMed: 16232233]
46. Hueting WE, Gooszen HG, van Laarhoven CJ. Sexual function and continence after ileo pouch anal anastomosis: a comparison between a meta-analysis and a questionnaire survey. Int J Colorectal Dis. 2004; 19:215–218. [PubMed: 14564464]
47. Damgaard B, Wettergren A, Kirkegaard P. Social and sexual function following ileal pouch-anal anastomosis. Dis Colon Rectum. 1995; 38:286–289. [PubMed: 7882794]
48. Lindsey I, George BD, Kettlewell MG, et al. Impotence after mesorectal and close rectal dissection for inflammatory bowel disease. Dis Colon Rectum. 2001; 44:831–835. [PubMed: 11391143]
49. Kjaer MD, Laursen SB, Qvist N, et al. Sexual Function and Body Image are Similar after Laparoscopy-Assisted and Open Ileal Pouch-Anal Anastomosis. World J Surg. 2014
50. Eshuis EJ, Polle SW, Slors JF, et al. Long-term surgical recurrence, morbidity, quality of life, and body image of laparoscopic-assisted vs. open ileocolic resection for Crohn's disease: a comparative study. Dis Colon Rectum. 2008; 51:858–867. [PubMed: 18266036]
51. Bambrick M, Fazio VW, Hull TL, et al. Sexual function following restorative proctocolectomy in women. Dis Colon Rectum. 1996; 39:610–614. [PubMed: 8646943]
52. Cornish J, Wooding K, Tan E, et al. Study of sexual, urinary, and fecal function in females following restorative proctocolectomy. Inflamm Bowel Dis. 2012; 18:1601–1607. [PubMed: 22275287]
53. Bengtsson J, Lindholm E, Nordgren S, et al. Sexual function after failed ileal pouch-anal anastomosis. J Crohns Colitis. 2011; 5:407–414. [PubMed: 21939914]
54. El-Gazzaz G, Hull T, Mignanelli E, et al. Analysis of function and predictors of failure in women undergoing repair of Crohn's related rectovaginal fistula. J Gastrointest Surg. 2010; 14:824–829. [PubMed: 20232172]
55. Yoshida K, Araki T, Uchida K, et al. Sexual activity after ileal pouch-anal anastomosis in Japanese patients with ulcerative colitis. Surg Today. 2014; 44:73–79. [PubMed: 23440359]
56. Serretti A, Chiesa A. Treatment-emergent sexual dysfunction related to antidepressants: a meta-analysis. J Clin Psychopharmacol. 2009; 29:259–266. [PubMed: 19440080]
57. Feagins LA, Kane SV. Sexual and reproductive issues for men with inflammatory bowel disease. Am J Gastroenterol. 2009; 104:768–773. [PubMed: 19223893]
58. Fass R, Fullerton S, Naliboff B, et al. Sexual dysfunction in patients with irritable bowel syndrome and non-ulcer dyspepsia. Digestion. 1998; 59:79–85. [PubMed: 9468103]
59. Kennedy SH, Dickens SE, Eisfeld BS, et al. Sexual dysfunction before antidepressant therapy in major depression. J Affect Disord. 1999; 56:201–208. [PubMed: 10701478]

60. Mikocka-Walus AA, Turnbull DA, Moulding NT, et al. Controversies surrounding the comorbidity of depression and anxiety in inflammatory bowel disease patients: a literature review. Inflamm Bowel Dis. 2007; 13:225–234. [PubMed: 17206706]
61. El-Salhy M. Irritable bowel syndrome: diagnosis and pathogenesis. World J Gastroenterol. 2012; 18:5151–5163. [PubMed: 23066308]
62. Halpin SJ, Ford AC. Prevalence of symptoms meeting criteria for irritable bowel syndrome in inflammatory bowel disease: systematic review and meta-analysis. Am J Gastroenterol. 2012; 107:1474–1482. [PubMed: 22929759]
63. Maggiori L, Panis Y. Surgical management of IBD--from an open to a laparoscopic approach. Nat Rev Gastroenterol Hepatol. 2013; 10:297–306. [PubMed: 23419288]
64. Davies RJ, O'Connor BI, Victor C, et al. A prospective evaluation of sexual function and quality of life after ileal pouch-anal anastomosis. Dis Colon Rectum. 2008; 51:1032–1035. [PubMed: 18454295]
65. Wang JY, Hart SL, Wilkowski KS, et al. Gender-specific differences in pelvic organ function after proctectomy for inflammatory bowel disease. Dis Colon Rectum. 2011; 54:66–76. [PubMed: 21160316]
66. Lindsey I, George B, Kettlewell M, et al. Randomized, double-blind, placebo-controlled trial of sildenafil (Viagra) for erectile dysfunction after rectal excision for cancer and inflammatory bowel disease. Dis Colon Rectum. 2002; 45:727–732. [PubMed: 12072621]
67. Larson DW, Davies MM, Dozois EJ, et al. Sexual function, body image, and quality of life after laparoscopic and open ileal pouch-anal anastomosis. Dis Colon Rectum. 2008; 51:392–396. [PubMed: 18213489]
68. Berndtsson I, Lindholm E, Ekman I. Thirty years of experience living with a continent ileostomy: bad restrooms--not my reservoir--decide my life. J Wound Ostomy Continence Nurs. 2005; 32:321–6. quiz 327–8. [PubMed: 16234726]
69. Eshuis EJ, Slors JF, Stokkers PC, et al. Long-term outcomes following laparoscopically assisted versus open ileocolic resection for Crohn's disease. Br J Surg. 2010; 97:563–568. [PubMed: 20175126]
70. Scarpa M, Ruffolo C, Bassi D, et al. Intestinal surgery for Crohn's disease: predictors of recovery, quality of life, and costs. J Gastrointest Surg. 2009; 13:2128–2135. [PubMed: 19779944]
71. Camilleri-Brennan J, Munro A, Steele RJ. Does an ileoanal pouch offer a better quality of life than a permanent ileostomy for patients with ulcerative colitis? J Gastrointest Surg. 2003; 7:814–819. [PubMed: 13129563]
72. O'Bichere A, Wilkinson K, Rumbles S, et al. Functional outcome after restorative panproctocolectomy for ulcerative colitis decreases an otherwise enhanced quality of life. Br J Surg. 2000; 87:802–807. [PubMed: 10848862]
73. Rosen RC, Riley A, Wagner G, et al. The international index of erectile function (IIEF): a multidimensional scale for assessment of erectile dysfunction. Urology. 1997; 49:822–830. [PubMed: 9187685]
74. Rosen R, Brown C, Heiman J, et al. The Female Sexual Function Index (FSFI): a multidimensional self-report instrument for the assessment of female sexual function. J Sex Marital Ther. 2000; 26:191–208. [PubMed: 10782451]
75. Quirk FH, Heiman JR, Rosen RC, et al. Development of a sexual function questionnaire for clinical trials of female sexual dysfunction. J Womens Health Gend Based Med. 2002; 11:277–289. [PubMed: 11988137]
76. Stewart, AL.; Ware, JE. Measuring Functioning and Well-being: The Medical Outcomes Study Approach. Duke University Press; 1992.
77. Hopwood P, Fletcher I, Lee A, et al. A body image scale for use with cancer patients. Eur J Cancer. 2001; 37:189–197. [PubMed: 11166145]
78. de Rooy EC, Toner BB, Maunder RG, et al. Concerns of patients with inflammatory bowel disease: results from a clinical population. Am J Gastroenterol. 2001; 96:1816–1821. [PubMed: 11419835]
79. Baxter NN, Novotny PJ, Jacobson T, et al. A stoma quality of life scale. Dis Colon Rectum. 2006; 49:205–212. [PubMed: 16392025]

80. Mahadev S, Young JM, Selby W, et al. Quality of life in perianal Crohn's disease: what do patients consider important? Dis Colon Rectum. 2011; 54:579–585. [PubMed: 21471759]

81. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992; 30:473–483. [PubMed: 1593914]

82. Guyatt G, Mitchell A, Irvine EJ, et al. A new measure of health status for clinical trials in inflammatory bowel disease. Gastroenterology. 1989; 96:804–810. [PubMed: 2644154]

83. Irvine EJ, Zhou Q, Thompson AK. The Short Inflammatory Bowel Disease Questionnaire: a quality of life instrument for community physicians managing inflammatory bowel disease. CCRPT Investigators. Canadian Crohn's Relapse Prevention Trial. Am J Gastroenterol. 1996; 91:1571–1578. [PubMed: 8759664]

84. Eypasch E, Williams JI, Wood-Dauphinee S, et al. Gastrointestinal Quality of Life Index: development, validation and application of a new instrument. Br J Surg. 1995; 82:216–222. [PubMed: 7749697]

85. Kiran RP, Delaney CP, Senagore AJ, et al. Prospective assessment of Cleveland Global Quality of Life (CGQL) as a novel marker of quality of life and disease activity in Crohn's disease. Am J Gastroenterol. 2003; 98:1783–1789. [PubMed: 12907333]

86. Rockwood TH, Church JM, Fleshman JW, et al. Fecal Incontinence Quality of Life Scale: quality of life instrument for patients with fecal incontinence. Dis Colon Rectum. 2000; 43:9–16. discussion 16–7. [PubMed: 10813117]

87. Drossman DA, Leserman J, Li ZM, et al. The rating form of IBD patient concerns: a new measure of health status. Psychosom Med. 1991; 53:701–712. [PubMed: 1758953]

88. de Zeeuw S, Ahmed Ali U, van der Kolk MB, et al. Ileal pouch anal anastomosis with close rectal dissection using automated vessel sealers for ulcerative colitis: a promising alternative. Dig Surg. 2011; 28:345–351. [PubMed: 22004850]

89. Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol. 1998; 51:1055–1068. [PubMed: 9817123]

Table I

Summary of Studies Examining Sexual Functioning and Quality of Life in IBD Patients

Authors	Year	Total (N)	Diagnosis (N)	Surgery (N)	Sexual Functioning Measure	Sexual Functioning Results	QoL Measure	Quality of Life Results	SF and QoL Associations
Bengtsson et al.	2011	108	UC	Failed Pouch (36), Functioning Pouch (72)	FSFI, IIEF	No differences on any of the FSFI or IIEF domains were found b/t pts with pouch failure vs those with functioning pouch; Median summary scores for men and women in pouch failure group were below cut-offs for SD	SF-36	Men/women with pouch failure scored lower on all SF-36 domains, compared to men/women with functioning pouch; only the social function domain for men was statistically significant	
Cornish et al.	2012	109	IBD (54, RPC), UC no stoma or RPC (55)	RPC	FSFI	No differences on all domains b/t patients who had RPC compared to those who did not	SF-36	Overall physical health and bodily pain were significantly better among UC pts who did not have RPC; No significant differences were found on general health, overall mental health or social role domains	
Da Silva et al.	2008	93	Benign (154), malignant disease (32)	Pelvic (57), abdominal (36)	FSFI	Overall SF had significantly deteriorated 6-mo post-operatively, with partial recovery at 12-mo	SF-36	For both groups, mental status improved significantly at 12-months, and physical status improved significantly at 6 months; patients	MCS scores improved over time, with significant improvement (p= 0.007) at 12 months. PCS scores demonstrated significant improvement

Authors	Year	Total (N)	Diagnosis (N)	Surgery (N)	Sexual Functioning Measure	Sexual Functioning Results	QoL Measure	Quality of Life Results	SF and QoL Associations
								undergoing abdominal surgery had faster physical sta undergoing abdominal surgery had faster physical sta undergoing abdominal surgery had faster physical sta undergoing abdominal surgery had faster physical sta undergoing abdominal surgery had faster physical sta undergoing abdominal surgery had faster physical sta	at 6 months (but no significant improvement between 6 and 12 months). Better sexual functioning was also observed among women with higher MCS and PCS scores at 6 months.
Davies et al.	2008	59	UC (54), IC (1), FAP (4)	IPAA	FSFI, IIEF	Male SF scores remained high post-operatively; Post-operatively, female SF improved significantly and female SD decreased significantly	S-IBDQ	Men and women demonstrated statistically significant improvement at 6- and 12-months post-operatively	
El-Gazaaz et al.	2010	28	CD: healed (15), unhealed (14)	Surgery for rectovaginal fistulas	FSFI	No significant differences on all domains between healed and unhealed patients	SF-12, FIQL	No significant differences on both measures between healed and non-healed pts	
Hueting et al.	2004	111	IBD	IPAA	Self-created questions on SF	SD=19.8%; Impotence or retrograde ejaculation=25.7%; Dyspareunia = 30.3%	Self-created questions on QoL, and QoL rating 0–10	90% were satisfied with IPAA; 71% felt no general restrictions after IPAA; 78% felt QoL improved after IPAA	
Kjaer et al.	2014	50	UC (44), FAP (4), other (2)	L-IPAA (28), O-IPAA (22)	FSFI, IIEF	No significant differences on any domain between L-IPAA vs O-IPAA groups; Median scores on SF for men in both groups and women in L-IPAA were normal; Median scores for women in O-IPAA demonstrated SD	S-IBDQ	No significant differences were found between pts who had L-IPAA and those who had O-IPAA; Median	

Authors	Year	Total (N)	Diagnosis (N)	Surgery (N)	Sexual Functioning Measure	Sexual Functioning Results	QoL Measure	Quality of Life Results	SF and QoL Associations
								scores in both groups indicate some impairment in Qo	
								scores in both groups indicate some impairment in Qo	
								scores in both groups indicate some impairment in Qo	
								scores in both groups indicate some impairment in Qo	
Larson et al.	2008	125	UC and FAP	L-IPAA (46), O-IPAA (79)	FSFI, IIEF	No significant differences on any domain between women in L-IPAA vs O-IPAA; Women in both grps demonstrated SD; Men in the L-IPAA group demonstrated significantly lower orgasmic function compared to men in the O-IPAA group	SF-8	No significant differences were found between pts who had L-IPAA vs those who had O-IPAA; Mean scores on physical and mental health for both groups were within normal range	
Muller at al.	2010	217	UC (85), CD (127), IC (5)	N/A	Self-created questions on SF	50% felt that IBD negatively affected their relationship status; 58% reported that frequency of sex was decreased by IBD; Female gender had a statistically significant negative impact on libido and frequency of sex	Single Q: “Has IBD ever affected QoL?”	88.5% reported that QoL had been affected by IBD	
Riss et al.	2012	168	CD (69), healthy controls (69)	Surgery for anal fistulas	FSFI, IIEF	No significant differences on any domains between patients and controls; SD was high among female pts and female controls	SF-12, IBDQ	Median SF-12 physical health score was significantly lower among patients, compared to controls; Pts also demonstrated significnatly poorer IBDQ scores	
Slors et al.	2000	76	UC (65), FAP (10), CC (1)	Mesorectal Excision	Self-created questions on SF	Sexual activity, satisfaction and libido were better among males; incidental ED found in 7.5%; dyspareunia found in 41.7%	QoL rating 0–10	Significant improvement in QoL for UC pts; No differences in QoL between men and women	No correlation b/t QoL and sexual dysfunction

Authors	Year	Total (N)	Diagnosis (N)	Surgery (N)	Sexual Functioning Measure	Sexual Functioning Results	QoL Measure	Quality of Life Results	SF and QoL Associations
van Balkom et al.	2012	23	UC (16), FAP (10)	RPC with IPAA	FSFI, IIEF	None of the men demonstrated sexual dysfunction and none reported impotence or retrograde ejaculation; 50% of women reported sexual dysfunction	SF-36; GIQLI	QoL scores were lower among men/ women compared to normative data	Male and female sexual function were highly correlated (r=0. 70) with QoL: PCS and MCS and GIQLI total scores although the correlation only trended toward significance (p=0.08).
Wang et al.	2011	66	UC (56), CD (10)	IPAA (48), Permanent End ileostomy (18)	FSFI, IIEF, SFQ	SF-36, IBDQ	Men/women with IPAA demonstrated significant improvement on SF-36 and IBDQ scales; Men/women with permanent end ileostomies did not demonstrate improvement on SF-36; Men demonstrated improvement on emotional health subscale of IBDQ		
Yoshida et al.	2014	61	UC	IPAA	Sex life question from IBDQ; Self-created questions on SF	32% reported SD; no significant differences in SF between men and women;	IBDQ-Japanese		Social functions other than Sex life correlated with SF; significant difference in scores for Social functions other than Sex life between pts with poor and good sexual activity;

Authors	Year	Total (N)	Diagnosis (N)	Surgery (N)	Sexual Functioning Measure	Sexual Functioning Results	QoL Measure	Quality of Life Results	SF and QoL Associations
									scores for Bowel, Systemic and Em
									scores for Bowel, Systemic and Em
									scores for Bowel, Systemic and Em
									scores for Bowel, Systemic and Em
									scores for Bowel, Systemic and Em
									scores for Bowel, Systemic and Em
									scores for Bowel, Systemic and Em

Notes:

IBD=Inflammatory Bowel Disease, SF=Sexual function, SD=Sexual dysfunction, UC=Ulcerative Colitis, CD=Crohn's Disease, IC=Indeterminate Colitis, FAP=Familial adenomatous polyposis, CC=Chronic Constipation, ED=Erectile dysfunction, Pts=patients, FSFI=Female Sexual Function Index, IIEF=International Index of Erectile Function, SFQ=Sexual Function Questionnaire, FIQL=Fecal Incontinence Quality of Life Scale, L-IPAA=Laparoscopic Ileal Anal Anastomosis, O-IPAA=Open Ileal Anal Anastomosis, GIQLI=Gastrointestinal Quality of Life Index, BISF-W=Brief Index of Sexual Function in women, IBDQ=Inflammatory Bowel Disease Quality of Life Questionnaire, S-IBDQ=Short Form Inflammatory Bowel Disease Questionnaire; PCS=Physical Component Summary of SF-36; MCS =Mental Component Summary of SF-36

Table 2

Summary of Studies Examining Body Image and Quality of Life in IBD Patients

Authors	Year	Total N	Diagnosis (N)	Surgery (N)	Body Image Measure	Body Image Results	Quality of Life Measure	Quality of Life Results	BI and QoL Associations
Camilleri-Brennan et al.	2003	36	UC	IPAA(19), PPC+I (19)	Self-created BI questions	IPAA better BI than PPC+I	SF-36 and IBDQ	No difference between groups in QoL on either measure	
Carlsson et al.	2003	21	CD (14), UC (6), IC (1)	Ileostomy	Single item of the RFIPC	"Feelings about the body" ranked #9 of 24 potential concern areas	RFIPC, SF-36, 2 QoL interview questions, 3 VAS QoL questions	Ileostomy patients scored lower on vitality but no other areas of QoL on SF-36	
de Rooy et al.	2001	241	CD (120), UC (120)		Single item of the RFIPC	"Feelings about the body" ranked #10 of 25 potential concern areas in CD+UC group, BI item assoc with inability to work due to IBD	RFIPC	UC patients had greater concerns of developing cancer, no other group differences	
Dunker et al.	2001	32		L-IPAA (15), O-IPAA (17)	BIQ	Cosmetic satisfaction higher L-IPAA vs O-IPAA, BI trended to be higher L-IPAA vs O-IPAA (p=.09), no difference in BI or cosmetic satisfaction by 2- vs 1-stage procedure or by gender or age	SF-36 and GIQLI	Overall QoL on SF-36 and the GIQLI did not differ between groups, global physical functioning higher in L-IPAA than O-IPAA	
Dunker et al.	1998	34	CD	OIR (11), LIR (11), NR (12)	BIQ and PSQ	BI non-significantly better LIR vs OIR, LIR more satisfied with scar vs OIR, no differences in BI by gender, cosmetics scale scores higher LIR vs OIR, men higher cosmetics vs women, LIR graded scars higher vs OIR	IBDQ (Dutch version)	NR higher QoL than OIR or LIR (non-significant), men better QoL vs women particularly bowel symptoms and social functioning	BI correlated significantly positively with QoL, no association between cosmetics score and QoL
Eshuis et al.	2008	61	CD	OIR (38), LIR (23)	BIQ and PSQ	No differences in BI LIR vs OIR, cosmetics score	SF-36 and GIQLI	No significant differences in QoL (SF-36 or	

Authors	Year	Total N	Diagnosis (N)	Surgery (N)	Body Image Measure	Body Image Results	Quality of Life Measure	Quality of Life Results	BI and QoL Associations
						higher LIR vs OIR, LIR rated scars higher vs OIR,		GIQLI, LIR moderate to be higher vs OIR, OIR and LIR lower QoL total and subscale scores on (SF-36, except MH subscale) vs healthy matched controls	no gender differences in BI or cosmesis or scar rating
Eshuis et al.	2010	53	CD	OIR (25), LIR (28)	BIQ and PSQ	BI and cosmesis scores higher LIR vs OIR, LIR rated scars higher vs OIR	SF-36 and GIQLI	No differences in QoL (SF-36 or GIQLI), LIR+OIR higher SF-36 MH subscale and lower Vitality, General Health Perception, and PCS vs healthy matched controls	
Kjaer et al.	2014	50		O-IPAA (22), L-IPAA (28)	BIQ	No differences in BI, trend to better BI in women with L-IPAA vs O-IPAA	SIBDQ	No differences in QoL between groups	
Knowles et al.	2013	31	CD	Ileostomy	Subscale of SQOL	No differences on sexuality/body image subscale, poorer sexuality/body image correlated with more depression and more illness beliefs	SQOL	No differences in QoL by gender, ostomy surgery timing, type of stoma, number of ostomy surgeries, or use of psychological services	
Larson et al.	2008	125		O-IPAA (79), L-IPAA (46)	BIQ	No differences in BI or cosmesis by surgeries for men or women	SF-8	No differences in QoL by surgeries for men or women	

Authors	Year	Total N	Diagnosis (N)	Surgery (N)	Body Image Measure	Body Image Results	Quality of Life Measure	Quality of Life Results	BI and QoL Associations
Mahadev et al.	2011	69	Perianal CD		Subscale of self-created CD-specific QoL questionnaire	Cosmetic appearance less important area of concern compared to physical, functional, and emotional concerns	Self-constructed CD-specific QoL questionnaire	Physical symptoms rated as highly important for QoL, females rated physical and emotional aspects of QoL highly	
Muller et al.	2010	217	CD (127), UC (85), IC (5)		Component of a self-constructed questionnaire on patient perceptions of IBD impact	IBD impaired BI in 66.8% of pts, females and operated patients (females only) greater impact of IBD on BI, no difference by CD/UC diagnosis	Component of a self-constructed questionnaire on patient perceptions of IBD impact	QoL impaired by IBD in 88.5% of pts, no difference by genders, disease types, or operated versus non-operated	
Polle et al.	2007	46	UC or FPC	O-IPAA (23), L-IPAA (23)	BIQ and PSQ	No pre- and post-op BI differences, post-op cosmesis higher in L-IPAA vs O-IPAA, post-op BI and cosmesis higher L-IPAA vs O-IPAA in females, females lower BI vs males in O-IPAA, L-IPAA rated scars better vs O-IPAA	SF-36 and GIQLI	QoL improved from 3-month to 12 months post-op (SF-36 and GIQLI), no difference in QoL by surgery	
Scarpa et al.	2009	47	CD		BIQ	BI independently predicted by disease activity and use of laparoscopic surgery	CGQL	QoL correlated with disease activity, surgical complications, and Barthel's Index, disability status at admission primary predictor of QoL, no difference in QoL by surgery	
van Balkom et al.	2012	23	UC or FAP	IPAA	BIQ	Females poorer BI (p=.08) and lower cosmesis (p=.07), BI	SF-36 and GIQLI	QoL correlated negatively	No significant correlations

Authors	Year	Total N	Diagnosis (N)	Surgery (N)	Body Image Measure	Body Image Results	Quality of Life Measure	Quality of Life Results	BI and QoL Associations
						and cosmesis did not correlate with each other and cosmesis did not correlate with each other and cosmesis did not correlate with each other		with impairment of bowel function (SF-36 and GIQLI), no associations QoL and diagnosis	between BI and QoL (SF-36 and GIQLI)

Notes:

IBD = Inflammatory Bowel Disease, UC= Ulcerative colitis, CD= Crohn's disease, IC = Indeterminate colitis, FAP= Familial Polyposis Coli, IPAA= Proctocolectomy with ileal pouch-anal anastomosis, PPC+I= Panproctocolectomy and permanent (Brooke) ileostomy, L-IPAA=Laparoscopic-assisted ileal pouch-anal anastomosis, O-IPAA= Conventional ileal pouch-anal anastomosis, OIR= Open ileocolic resection, LIR= Laproscopic-assisted ileocolic resection, NR= No resection, QoL= Quality of life, BI= Body image, RFIPC = Ratings Form of IBD Patient Concerns, PSQ= Photo Series Questionnaire, BIQ= Body Image Questionnaire, IBDQ= Inflammatory Bowel Disease Questionnaire, SF-36 = Short-Form Health Survey, VAS= Visual analog scale, GIQLI= Gastrointestional Quality of Life Index, SIBDQ= Short Inflammatory Bowel Disease Questionnaire, SQOL= Stoma Quality of Life Scale, SF-8= Short-Form Health Survey, 8 item version, CGQL-Cleveland Global Quality of Life instrument