# Sexual Dysfunction in Puerto Rican Women with Inflammatory Bowel Disease

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**Objective: Inflammatory bowel disease (IBD) negatively impacts quality of life–related issues including intimacy, body image, and sexual activity. Sexual dysfunction in patients with IBD is often unrecognized. In this study, we aimed to describe sexual function in Puerto Rican women with IBD.**

**Methods: We conducted a cross-sectional study of women with IBD at the University of Puerto Rico Center for IBD. Patients were invited to anonymously complete the validated Spanish version of the Female Sexual Function Index (FSFI) questionnaire. On this 36-point scale, a score of 26.55 or less is defined as sexual dysfunction. Data were analyzed by diagnosis, presence of an ostomy, and age, using descriptive statistics, ANOVA, Student's *t* test, and logistic regression.**

**Results: One hundred women completed the FSFI questionnaire, with subjects having Crohn's disease (CD) outnumbering those having ulcerative colitis (UC) 2:1. The mean sexual function score was 21.92 (95% CI: 20.08–23.76). No statistical difference was observed in total FSFI scores between subjects with CD and UC (p = 0.084) and those with an ostomy (p = 0.891). Sexual function decreased with age (p = 0.001). The domains of excitation, lubrication, orgasm, and satisfaction were the most negatively affected (p<0.05) by increasing age. Multivariate analysis confirmed the effect of age on excitation, lubrication, orgasm, and pain.**

**Conclusion: Our study showed sexual dysfunction to be present in this sample of Puerto Rican Hispanic women with IBD. Physicians treating patients with IBD need to be aware of these findings to explore the concerns of individuals with this disease and develop strategies to address those concerns. [*P R Health Sci J 2020;39:243-248*]**

*Key words: Sexual dysfunction, Inflammatory bowel disease, Female*

Inflammatory bowel diseases (IBDs) are chronic conditions, of which Crohn's disease (CD) and ulcerative colitis (UC) are included. In Puerto Rico, the prevalence of IBD increased from 38.2 per 100,000 inhabitants (1) in 2005 to 181.54 per 100,000 in 2013 (2), with the highest prevalence for CD being in individuals aged from 20 to 39 years and for UC being in individuals aged 50 years and over (2). The increase in the number of patients with IBD in our Puerto Rican population mandates an evaluation of the characteristics of those patients and underlines the need to develop appropriate strategies of care.

Both physical and psychological factors affect patients with IBD. The complications of IBD may include perianal disease, fistulae and abscesses, and incontinence. Surgery is frequently necessary, sometimes including the placement of a stoma or pouch; intestinal resection is needed in 70 to 80% of all CD patients, and a proctocolectomy must be performed in 30 to 40% of all UC cases (3,4). However, despite these challenges, improvements in drug therapy and medical care in the last few decades have led to normal life expectancies for these patients (5).

The World Health Organization (WHO) proposed defining sexual health as a "state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity" (6). IBD is likely to have a substantial impact on body image, intimacy, and sexuality because of such accompanying manifestations as abdominal pain, fatigue, bloating, gas, diarrhea, incontinence, and perianal disease (7,8,9). Thus, the medical care of patients with IBD must address the clinical control of the disease as well as the normalization of each individual patient's quality of life

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(QOL). In women affected by IBD, the key issues related to sexuality include sexual dysfunction (9), negative body image (10), decreased fertility (10,11), the increased risk of specific adverse birth outcomes during pregnancy (12), and gynecologic manifestations (13). Muller et al. (10) reported that 66.8% of patients with IBD felt that their body image was impaired due to their IBD. Moody et al. (14) noted that women with CD had significantly more dyspareunia and less sexual intercourse than did age-matched controls. Timmer et al. (15) reported that although there were no differences between women with IBD and controls on the Brief Index of Sexual Function in Women, women with active disease felt less attractive and less feminine than did patients in remission. A meta-analysis by Zhao et al. (16) and a study by Bel et al. (9) both concluded that sexual dysfunction is present in most women with IBD. Riviere et al. (17) reported sexual dysfunction in 54% of women with IBD. Riss et al. (18) found that although surgery for perianal CD had a notable influence on QOL, such was not the case for sexual function.

Besides being genetically different from members of the mainland USA white population (19), Puerto Rican Hispanics are also culturally different. Studies to define disease characteristics in our population are important, but so are studies that evaluate the psychological and social impact of IBD while also considering the possible influence of cultural background on attitudes and behavior. Sexual function may be impacted by culture. Sexual dysfunction in females with IBD has been reported in various populations (9,10,15,16,17,20,21,22). Data on our Puerto Rican population are needed if we and other healthcare personnel are to develop appropriate evaluation and treatment strategies that address the needs of this population and that will result in better outcomes.

An important aspect of the evaluation of patients with IBD is the medical consultation. This allows the physician to subjectively elicit the impact of the disease and treatment on the patient and to assess both the patient's adaptation to the disease and his or her QOL. However, most instruments that evaluate QOL have few items about sexuality, attaching little clinical value to sexual function (22,23,24). To address this limitation and better understand our female patients' concerns, we evaluated sexual function in Puerto Rican women with IBD using an anonymous questionnaire and inquired about physician–patient communication regarding sexuality. The study described herein was intended to improve healthcare personnel's understanding of their Puerto Rican female patients and aid in the development of strategies to address the concerns of those patients.

## Material and Methods

### Recruitment

We conducted a cross-sectional study to evaluate sexual function in women with a confirmed diagnosis of IBD at least 4 weeks prior to their study participation. Subjects were recruited from the IBD Clinics of the University of Puerto Rico Medical Sciences Campus, a tertiary care center for patients diagnosed with CD or UC. The enrollment period was from January 1, 2015, to December 31, 2015. The investigators attended the IBD clinic weekly until the target of 100 subjects was reached. Adult women attending the clinic received a general explanation of the study, including written material, and had the opportunity to ask questions. Those who consented, verbally, to participate were administered 2 survey questionnaires regarding female sexual function. The study was approved by the University of Puerto Rico Medical Sciences Campus Institutional Review Board (IRB protocol #1250914).

### Participants

Female patients of the clinic were invited to participate if they were 21 years old or older, had a diagnosis of UC, indeterminate colitis, or CD, and had an appointment at the IBD clinic during the recruitment period. Age and diagnosis were self-reported by the subject, as no records were reviewed and no identifiers were requested or collected. The patients that attend the Center for IBD are in general well educated about their diagnosis. The exclusion criteria were being under 21, not having an established diagnosis of IBD, and being unwilling or unable to complete the self-administered questionnaire. A brief explanation of the study, accompanied by written information, was presented by the study personnel to each subject that fulfilled the inclusion criteria. Consent was verbal, as the surveys were completely anonymous and no personal identifying information was collected. A socio-demographic data form and 2 questionnaires were given to each subject. The subjects were escorted to a private room provided for answering the self-administered questionnaires. The participants placed their completed questionnaires in a plain envelope that was dropped into a box designated for that purpose. Study personnel were at hand to answer any questions.

### Questionnaires

A 3-part survey questionnaire was administered to each subject enrolled in our study; the questionnaire consisted of 1) socio-demographic characteristics, 2) the Female Sexual Function Index (FSFI), and 3) 5 simple questions regarding how they feel about discussing their sexuality with the physician. The information collected included age, diagnosis (CD, IC, or UC), the duration of their disease, the presence and—if present—duration of their ostomy, and the nature of their current intimate relationship, if they were in such a relationship at the time of the survey . The FSFI (25,26) is a brief multidimensional self-report instrument consisting of 19 questions covering 6 subscales: desire, arousal, lubrication, orgasm, satisfaction, and pain. Total scores can range from 2 to 36. High scores correlate with better sexual function, as described by the authors. The FSFI has good internal reliability and is also able to differentiate between clinical samples and non-dysfunctional controls, using a cut-off score of 26.55 (25,26). A Spanish version of the instrument was translated and validated by Blümel et al. (27). This version was reviewed by investigators and tested for comprehension

in healthy volunteers to assess applicability to a Puerto Rican population. Permission was obtained from Rosen to use the instrument. A second survey instrument, this one designed by the study's investigators, was also administered. Called the "Discussion About Sexuality in a Medical Appointment," the questionnaire consisted of 5 simple questions that explored the respondent's experience or experiences with discussing issues related to sexuality with a doctor or doctors (Table 1).

**Table 1**. The Discussion about Sexuality in a Medical Appointment (DSMA) Questions

| |
|---|
| 1. In your medical appointments, have you ever discussed any issue or issues related to sexuality with your doctor? |
| 2. If so, was your doctor the one who introduced the subject in the medical consultation? |
| 3. Is the doctor with whom you discussed the issue your gastroenterologist? If not, specify the specialty of that individual. |
| 4. Have you discussed the subject of sexuality with your physician(s) more than once? |
| 5. Do you feel comfortable discussing this issue with your doctor? |

### Statistical analyses

A descriptive analysis was performed to determine the frequencies and mean values. The FSFI was calculated according to the model of Rosen et al. (25). The results were stratified and a sub-analysis was performed by diagnosis (CD vs. UC), ostomy status, and age. Student's t test and ANOVA were used to analyze the socio-demographic and clinical characteristics of the subjects and the FSFI scores between groups. Logistic regression analysis was used to examine the effect of age on the relationship between IBD and each domain of the FSFI. Statistical analyses were performed using STATA v13.

## Results

### Demographic characteristics

A total of 100 adult women with IBD were enrolled in the study, with a response rate of 90% among all the qualifying clinic attendees. Recruitment was conducted in consecutive clinics, until the goal of 100 subjects was achieved. The majority (65%) of the subjects had CD. Most of the subjects reported having been diagnosed with IBD for 8 years or fewer (Table 2). The mean age of the study participants was 41 years old (SD ±15.1; range 21–87); a similar age distribution was observed between CD and UC. Most of the subjects reported having a sexual partner (80%). Only 10/96 had an ostomy, and all but 1 had CD. The durations of the ostomies ranged from 3 months to 5 years, though in 2 instances it had not been reported.

**Table 2**. Sociodemographic characteristics of patients expressed as frequency and percentage.

| | N (%) |
|---|---|
| Age | |
| 18–23 | 13 (13.0) |
| 24–29 | 16 (16.0) |
| 30–35 | 11 (11.0) |
| 36–41 | 14 (14.0) |
| 42–47 | 13 (13.0) |
| 48–53 | 10 (10.0) |
| 54–59 | 9 (9.0) |
| >59 | 14 (14.0) |
| Mean Age (± DS) | 41.2 (15.1) |
| Diagnosis | |
| Crohn's Disease | 66 (66.0) |
| Ulcerative Colitis | 33 (33.0) |
| Indeterminate Colitis | 1 (1.0) |
| Ostomy | |
| Yes | 10 (10.4) |
| No | 96 (89.6) |
| No Answer | 4 |
| Partner | |
| Yes | 80 (80.8) |
| No | 19 (19.2) |

### Female Sexual Function Index

The women with IBD reported abnormal sexual function, as defined by an FSFI score of less than 26; the mean FSFI score was 21.9 (95% CI: 20.1–23.8). There was no significant difference in dysfunction between women with CD and those with UC (p = 0.084). Women with UC had a lower score in the desire domain than did those with CD (p = 0.023) (Table 3). The mean scores in the remaining 5 domains and total FSFI score did not differ significantly by disease. Sexual function score decreased with increasing age (p = 0.001), as shown in Table 4. The excitation (p = 0.002), lubrication (p = 0.008), orgasm (p = 0.019), and satisfaction (p = 0.029) domains were the most affected by age. On multivariate analysis, age did not appear to have any effect on the relationship between IBD and desire (p = 0.289) or between IBD and satisfaction (p = 0.591). Age was

**Table 3**. FSFI Score by IBD diagnosis. The mean sexual function score was 21.92. Desire was affected in the subjects with UC but not in those with CD.

| | FSFI Score by Inflammatory Bowel Disease | | | |
|---|---|---|---|---|
| | Crohn's Disease | Ulcerative Colitis | Combined | p |
| Desire | 3.87 (95% CI: 3.56–4.17) | 3.29 (95% CI: 2.94–3.64) | 3.67 (95% CI: 3.43–3.91) | 0.023 |
| Arousal | 3.72 (95% CI: 3.30–4.15) | 3.02 (95% CI: 2.38–3.66) | 3.49 (95% CI: 3.13–3.84) | 0.064 |
| Lubrication | 4.00 (95% CI: 3.52–4.49) | 3.33 (95% CI: 2.62–4.04) | 3.78 (95% CI: 3.39–4.18) | 0.112 |
| Orgasm | 3.85 (95% CI: 3.38–4.32) | 3.41 (95% CI: 2.66–4.14) | 3.71 (95% CI: 3.31–4.10) | 0.286 |
| Satisfaction | 3.95 (95% CI: 3.51–4.39) | 3.28 (95% CI: 2.53–4.04) | 3.72 (95% CI: 3.34–4.12) | 0.107 |
| Pain | 3.64 (95% CI: 3.13–4.16) | 3.30 (95% CI: 2.58–4.04) | 3.54 (95% CI: 3.12–3.94) | 0.445 |
| Total | 23.05 (95% CI: 20.87–25.24) | 19.65 (95% CI: 16.26–23.04) | 21.92 (95% CI: 20.08–23.76) | 0.084 |

**Table 4**. FSFI score by domain and age. Sexual function decreased by age.

| | FSFI Score by Age | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Age (years) | | | | | | | | | | |
| | 18–23 | 24–29 | 30–35 | 36–41 | 42–47 | 48–53 | 54–59 | >59 | Total | *f* | *p* |
| Desire | 4.2 | 4.1 | 4.1 | 3.6 | 3.5 | 3.5 | 3.1 | 3.1 | 3.7 | 1.95 | 0.070 |
| Arousal | 4.1 | 4.5 | 4.2 | 3.2 | 3.4 | 3.3 | 3.3 | 1.9 | 3.5 | 3.62 | 0.002 |
| Lubrication | 4.3 | 5.0 | 4.4 | 3.8 | 3.8 | 3.0 | 3.4 | 2.25 | 3.8 | 2.97 | 0.008 |
| Orgasm | 4.5 | 5.0 | 4.1 | 3.3 | 3.4 | 3.5 | 4.0 | 1.9 | 3.7 | 2.54 | 0.019 |
| Satisfaction | 5.0 | 4.3 | 4.1 | 3.4 | 3.2 | 3.5 | 4.1 | 2.4 | 3.8 | 2.36 | 0.029 |
| Pain | 4.1 | 4.7 | 3.9 | 2.8 | 3.9 | 3.4 | 3.4 | 2.1 | 3.6 | 1.66 | 0.071 |
| Total | 26.2 | 27.6 | 24.9 | 20.2 | 21.3 | 20.3 | 21.4 | 13.7 | 22.0 | 3.80 | 0.001 |

found to have an effect on the relationship between IBD and excitation (p = 0.0232), lubrication (p = 0.0342), orgasm (p = 0.0168), and pain (p = 0.0375).

We did not find a significant difference in the FSFI scores of those with an ostomy (p = 0.891). The scores for the individual domains were also similar between subjects with an ostomy and those without, and no association with age or the duration of the ostomy was identified, either.

### Discussion about Sexuality in a Medical Appointment

Only 24 women had discussed their sexuality with a physician: 9 had UC, 1 had indeterminate colitis, and 14 had CD. The mean age of these women was 43.46 (+ 16.62) years, with a range of 21 to 76 years. For only 7 of the 24 (29.1%) women, the subject of sexuality had been introduced by the health professional, and only 1 of these 7 physicians had been a gastroenterologist. Of all the women who had discussed the subject with a physician, 11 (45.8%) had done so with a gastroenterologist, and the remainder had discussed it with a gynecologist. Fifteen of the 24 had discussed the subject more than once, 10 with a gynecologist. Most (11/15) of the participants reported that they had felt comfortable discussing the subject.

## Discussion

Sexuality is an important component of QOL. In patients with IBD, it is particularly important, since the disease usually starts during adolescence or young adulthood, a time when these patients experience developmental milestones important to sexual health (28). To improve QOL in patients with IBD, physicians need to address every aspect of these patients' everyday lives. In this study, our research group surveyed sexual function in adult women with IBD and specific areas of dysfunction regarding their sexuality.

Sexual health issues in patients with IBD have been described. Prior studies have demonstrated that growth and development, body image, intimacy, sexual functioning, fertility, and pregnancy may be influenced by IBD or the medical and surgical interventions used for its treatment (10,17,28). Many studies have been published regarding the evaluation of female sexual dysfunction among subjects with IBD (9,15,16,17,18,20,21,22,29). To our knowledge this is the first study to assess sexual dysfunction in Puerto Rican women with IBD.

In our study, the subjects had demographic characteristics similar to those described in other studies (9,10). The high percentage of participants with CD may represent a referral bias of our specialized IBD center towards more complex cases, which percentage differs from the prevalence distributions in Puerto Rico reported by Vendrell et al. (1) and Torres et al. (2). Comparable to what was seen in previous studies (9,10,14,22), our subjects were young (mean age at evaluation, 42 years). As the response rate was 90%, it is unlikely that there was an age bias in the recruited group. Similar to what was seen in other studies, only 10.4% of our subjects had an ostomy at the moment of the survey (9,15).

Our study replicates the previously reported finding of sexual dysfunction in women with IBD (9,10,15,16,17,18,20,21,22,29). Women with IBD were found, based on the FSFI instrument, to have severe sexual dysfunction. Patients with UC had a lower score on the FSFI compared with patients with CD (19.65 vs. 23.05, respectively); however, this result was not statistically significant (p>0.05). As we did not evaluate disease activity, this potential confounder cannot be excluded. All the evaluated domains were affected (domain score <5). Bel et al. (9), using the FSFI, found no difference in the prevalence of sexual dysfunction between women with IBD and controls from a general practice (52% vs. 44%, respectively). However, women with active disease had lower scores than those in remission did, and there was a significant association between disease activity and sexual function (9). Timmer et al. (15), using the Brief Index of Sexual Function in Women, reported low sexual activity in women with IBD. Depression was strongly associated with sexual dysfunction, a finding also reported by Mahmood (20). These 3 studies concluded that disease activity, depression, and fatigue may play discrete roles in the low scores that were obtained on the sexual function index (9,15,21). Though Riviere et al. (17) found an association between sexual dysfunction and both anxiety and social and emotional functioning in women with IBD, no such association was found between sexual dysfunction and disease activity.

In our cross-sectional study, age was found to be a variable that affected women's sexual function. In our subjects, sexual dysfunction was more prominent in the members of the older age groups (p<0.05). This finding was also observed by Blümel et al. in an FSFI Spanish language validation study that reported

that healthy women's sexuality reached its maximum expression from the ages of 35 to 40 and then declined (27). This was especially apparent in women older than 44, in whom sexual dysfunction increased. This is different than what Zhao et al. (16) reported in their meta-analysis, in which it was found that women with IBD who were younger than 40 had a higher risk of sexual dysfunction than did their 40+ counterparts. In their validation study, Blümel et al. found a decrease in desire and excitation after these women reached 40 years of age (27). In another study, Blümel and his group also found a high prevalence of sexual dysfunction in a cohort of healthy, middle-aged, Latin American women, in whom vaginal lubrication was the most important associated risk factor (21). In our population of women with IBD, we observed that the sexual domains that were most affected were arousal, lubrication, orgasm, and satisfaction ($p<0.05$) rather than desire or excitation. Multivariate analysis confirmed the effect of age on the domains of excitation, lubrication, orgasm, and pain but not on those of desire or satisfaction. We suggest that age may be an important independent factor in the sexual dysfunction found in some older women with IBD.

To our knowledge, this is one of the few studies that presents the worrisome reality of IBD-related sexual dysfunction in a Hispanic population. Even though our study demonstrates a significant decrease in sexual function in this population, our findings are limited by several factors. In our analysis, the confounders were not evaluated as potential causes of sexual dysfunction. The number of subjects who had an ostomy was too small to arrive at any conclusion related to this variable, but their FSFI scores were similar to those in subjects without an ostomy. Important aspects for future exploration are the effects of depression, anxiety, fatigue, disease activity, and the history of surgery for IBD, all which have been linked to sexual dysfunction. Depression has been identified as the most consistent factor that negatively affects sexual function in patients with IBD (14,15,22,28,29,30), whereas the role of past surgeries in women is controversial (18,29,31). Another limitation of our study was the impact of ethnicity and cultural competence on sexual-function studies in Hispanic women, as attitudes and beliefs related to cultural and religious background may also play a role in sexual dysfunction. Unfortunately, the FSFI has not been validated in Puerto Ricans (a unique Hispanic subpopulation), thus studies of sexual functioning in a control population should be included to remove cultural beliefs and behaviors as confounders for dysfunction.

Physicians who have female patients with IBD must educate themselves regarding the high prevalence of sexual dysfunction in this population.

Our data show significant sexual dysfunction in Hispanic women with IBD, regardless of the specific type of IBD (Crohn's disease or ulcerative colitis), or of the presence of an ostomy. Our subjects revealed that even though they may have been having sexual problems, it was not a topic typically discussed in the medical consultation. This was also noted in a study by Mahmood et al. (20). It is worth noting that although our group was small, most of the women felt comfortable discussing the subject of their sexuality with their physicians. Further educational studies may be directed towards improving patient–physician communication regarding sexual function and evaluating the possible confounding factors in this population, which factors might include depression, fatigue, surgery, or active disease. We stress that women with IBD are a population at risk of developing sexual dysfunction, and it is imperative for physicians to address this issue during the medical consultation.

## Resumen

Objetivo: La enfermedad inflamatoria intestinal (EII) impacta negativamente la calidad de vida, incluyendo intimidad, imagen corporal y actividad sexual. La disfunción sexual en pacientes con EII frecuentemente pasa desapercibida. Este estudio describe la función sexual en mujeres puertorriqueñas con EII. Métodos: Estudio de corte transversal en mujeres con EII atendidas en el Centro para EII de la Universidad de Puerto Rico. Las pacientes fueron invitadas a completar la versión validada en español del cuestionario Índice de Función Sexual Femenina (FSFI, en inglés) de forma anónima. Una puntación de 26.55 o menos, en una escala de 36, está definida como disfunción sexual. Los datos se analizaron por diagnóstico, presencia de ostomía y edad con estadísticas descriptivas, ANOVA, prueba de t de Student y regresión logística. Resultados: Cien mujeres completaron el cuestionario FSFI. La proporción de diagnóstico de Crohn versus colitis ulcerosa fue 2:1. La media de puntuación de función sexual fue 21.92 (95% IC: 20.08-23.76). No se observó diferencia estadística en la puntuación total de FSFI entre mujeres con Crohn y colitis ulcerosa ($p=0.084$) ni con o sin ostomía ($p=0.891$). La función sexual disminuyó con la edad ($p=00.001$). Los dominios de excitación, lubricación, orgasmo y satisfacción fueron los más afectados negativamente por el aumento en edad ($p<0.05$). Análisis multivariado confirmó el efecto de edad en la excitación, lubricación, orgasmo y dolor. Conclusión: Nuestro estudio demuestra disfunción sexual en mujeres hispanas puertorriqueñas con EII. Los médicos que atienden pacientes con EII deben explorar las preocupaciones de estas pacientes y desarrollar estrategias para atenderlas.

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