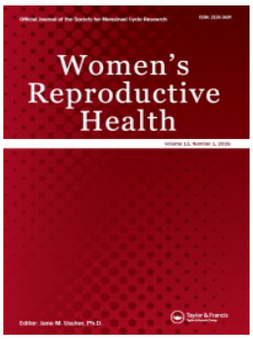

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An Exploration of Sexual and Reproductive Health of Australian Women Living with Inflammatory Bowel Disease: A Mixed Methods Study

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ABSTRACT

Inflammatory bowel disease (IBD) is an unpredictable condition that is more prevalent in females (57%) and commonly presents during reproductive years. This study explored the sexual and reproductive health of women who live with IBD in Australia using an online survey and interviews (March–November 2024). Survey responses from 64 women and qualitative data from 14 interviews highlighted menstrual changes, misinformation received regarding fertility, and the impact of IBD on women's sexuality. Findings from this study highlight the need to ensure discussions about sexuality are more actively incorporated into clinical care for women with IBD.

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Women; inflammatory bowel disease; ulcerative colitis; Crohn's disease; sexual well-being; sexual and reproductive health

Introduction

Inflammatory bowel diseases (IBD) including Crohn's disease (CD) and ulcerative colitis (UC) are chronic gastrointestinal diseases that present as unpredictable relapsing conditions. CD and UC both include inflammation of the intestinal tract that may result in abdominal pain, rectal bleeding, diarrhea, constipation, and bloating. Extraintestinal manifestations may also be experienced, which are characterized by several symptoms including, but not limited to, joint pain, painful skin conditions, inflammation of the eyes, and fatigue, all of which significantly impact on quality of life (Rogler et al., 2021; Woods, 2022).

Despite significant advances in medical management, IBD continues to pose major public health challenges with the worldwide prevalence estimated to be 6.8 million people (Global Disease Burden 2017 Inflammatory Bowel Disease Collaborators [GIBDC], 2020). Within Australia, the prevalence of IBD was projected to reach 100,000 by 2022 (Department of Health, 2019). The GIBDC (2020) identified that from the years 1990 to 2017 IBD was more prevalent in females (57%) than males (43%). The disease commonly manifests during the second to fourth decade of life (Armuzzi et al., 2022). This adds specific complexity for women as these are the years in which most women begin to menstruate, consider reproduction, and may begin perimenopause (Prior, 2020). While it is recognized that IBD can have far reaching negative impacts on a person's life, one aspect that remains underexplored is that of sexual and reproductive health. The sexual and reproductive health needs for women who live with IBD are not well understood. Additionally, the degree to which health professionals have the expertise to guide and support women regarding their sexual and reproductive health is not clear. A notable omission that was identified in a literature review (O'Reilly et al., 2025) was the lack of understanding about the impact that IBD has on women's sexuality more broadly. Many women have a sound understanding about the symptoms and management of IBD. However, it is unclear what the sexual and reproductive health needs are for women who live with IBD.

Women with IBD experience distinct challenges with findings from previous studies highlighting that many women who had active IBD reported higher rates of sexual dysfunction compared to women

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who did not have a diagnosis of IBD (Bel et al., 2015; Marín et al., 2013). Women with IBD have reported issues with vaginal lubrication and painful intercourse and a lack of reproductive knowledge with many believing all medications should be discontinued in pregnancy (Huang et al., 2015; Shmidt et al., 2019; Toomey & Waldron 2013; Walldorf et al., 2018). Achieving and maintaining disease remission before and during pregnancy is critical to optimize maternal and fetal outcomes (Prakash et al., 2024). Despite this, patient-centred guidance on family planning remains limited (Armuzzi et al., 2022). Additionally, Fourie et al. (2024) highlights that a changing body due to incontinence, stoma formation or placement of a seton drain for perianal disease, impacts on body image, placing strain on sexual well-being. Rather than self-initiate discussions about sexual and reproductive health due to initial discomfort, women wanted health care providers to raise the topic (Picciarelli et al., 2022).

This article presents findings from a mixed methods study exploring the sexual and reproductive health needs of women who live with IBD in Australia. The aim of this article is to present data that is specific to women's sexual and reproductive health. This has been done to inform and improve delivery of health care across the lifespan for women who live with this chronic health condition.

Methods

Design

The research was conducted using an equal weighting concurrent mixed methods design that included an online survey and qualitative interviews that aimed to explore the sexual and reproductive health needs for women who live with IBD in Australia. This article provides the analysis of the quantitative and qualitative data and uses the Good Reporting of a Mixed Methods Study (GRAMMS) checklist to report the findings (Supplementary File 1) (O'Cathain et al., 2008). Using mixed methods in research can be complementary (Thierbach et al. (2020). Using an online survey and qualitive interviews for this research allowed for each method to provide a more detailed and richer understanding of Australian women's sexual and reproductive health needs. A critical feminist standpoint is underpinned by the principle that experiences are informed by the social worlds in which we live (Naples & Gurr, 2014). Therefore, due to sex differences in reproductive anatomy for men and women, as well as socialized roles as indicated by Chrisler et al. (2020), using a feminist lens to bring women to the center was critical in all phases of the research from design to analysis and dissemination.

Survey

A search of the literature was conducted to explore whether there was an existing tool that explored women's sexual and reproductive health specific to IBD. No single comprehensive instrument was found by the authors. However, incorporating validated instruments following permissions into a single survey helped to answer the research question: What are the sexual and reproductive health needs for women who live with IBD? Prior to implementation, the survey was reviewed by two women who had a confirmed diagnosis of IBD to ensure suitability for the demographic. Minor adjustments were made following feedback to assist with readability and following ethics approval (H15913) the survey was uploaded onto the electronic platform Qualtrics™ and was live from March to November 2024. The anonymous online survey was arranged into six sections.

Demographic Information

Section A of the survey sought demographic information from participants such as age, diagnosis, relationship status, education, and employment status.

General Health

Section B pertained to women's general health (see Table 1) and used the SF-12 questionnaire designed by Ware et al. (1996). The scoring of the SF-12 was done using the standard regression-based scoring

algorithm developed by Ware et al. (1996). Scores are divided into two summary measures that comprise the Mental Component Summary (MCS) and the Physical Component Summary (PCS). For both of the previously named sections of the SF-12, scores above 50 indicate a better than average health related quality of life, whereas scores below 50 indicate below average health related quality of life (Ware et al., 1995).

Reproductive Health

Section C asked women about their reproductive health (see Table 1) and used the Women's Health Questionnaire (adapted with permissions) (Hunter, 1992). As not all questions were used from the Women's Health Questionnaire (WHQ), scoring was not carried out and data is presented as descriptive statistics.

Sexual Satisfaction

Section D asked participants about sexual satisfaction (see Table 1) using the Sexual Satisfaction Scale, adapted from the Sexual History Form by National Multiple Sclerosis Society (1997). Four questions are included in the scale and scoring can range from 4 to 24 with higher scores indicating greater sexual dissatisfaction.

Pregnancy Related Knowledge

Section E asked women about their pregnancy related knowledge (see Table 1) and used the Crohn's and Colitis Pregnancy Knowledge Scale developed by Selinger et al. (2012). As all participants in our study were women with a diagnosis of IBD, one question that related to the fertility of men with IBD was not included, leaving a total of sixteen questions. A score of 1 was given to the correct response with a possible range of scores between 0 and 16. Higher scores indicated participants had higher pregnancy related knowledge. Scores equal to or above 14 indicate very good IBD pregnancy knowledge (see Table 6).

Self-Esteem

Section F asked women if they felt their bodies looked different compared to before their diagnosis of IBD and if they were satisfied with their physical appearance. Additionally, section F asked women about self-esteem (see Table 1) using the Rosenberg's Self-Esteem Scale (Rosenberg, 1965). Scores above 25 indicate high self-esteem and scores below 15 indicate low self-esteem.

Reliability of a tool is rated between 0 and 1, with 0 indicating poor reliability and 1 indicating perfect reliability. Reliability ratings greater than 0.70 are considered optimal to ensure consistent measurement and accuracy of analysis that is important in this study and if comparative research is

Table 1. Validated tools incorporated within the sexual and reproductive health survey.

Tool name	Purpose	Reliability*
SF-12 Questionnaire (Ware et al., 1996).	Health-related quality of life measure.	Internal consistency: 0.91 Physical component 0.91 Mental component
Adapted (with permission) Women's Health Questionnaire [WHQ] (Hunter, 1992).	To assess women's menstrual cycles, screening practices and pregnancies.	Cronbach's alpha coefficient >0.70
Sexual Satisfaction Scale (Adapted from the Sexual History Form by National Multiple Sclerosis Society, 1997)	To assess women's satisfaction with sexual relationships.	Cronbach's alpha coefficient 0.91
Adapted (with permission) The Crohn's and Colitis Pregnancy Knowledge [CCPKnow] Tool (Selinger et al., 2012).	Assessing pregnancy knowledge related to inflammatory bowel disease.	Internal consistency: 0.94
Rosenberg's Self-Esteem Scale [RSES] (Rosenberg, 1965).	Evaluation of individuals self-esteem.	Internal consistency: 0.80

undertaken on this topic (Findler et al., 2001). All tools demonstrated reliability, with Cronbach's alpha coefficients ranging from 0.70 to 0.94. These are summarized in Table 1.

Interview

An interview guide was developed by (KO'R, EH, KP), all registered nurse academics, who have doctoral qualifications. The interview guide included questions such as: Can you tell me about the sexual and reproductive health changes felt or experienced since a diagnosis of IBD? Do these changes present challenges to you as a woman and how do you manage them? Can you tell me about your experience as a woman accessing health services. In what ways do you think being a woman with IBD has impacted your identity and how have you navigated this?

Data Collection

Australian women who self-identified as having a confirmed diagnosis of IBD, either UC or CD, were invited through Facebook™ and Twitter™ to complete an online survey and/or participate in semi-structured interviews between March and November 2024. Invitation to participate was also through online and print magazines and newsletters through Crohn Colitis Australia and Ostomy Australia. A participant information sheet was included at the beginning of the online survey outlining the study aims. Before interviews commenced and at times throughout conversations, concepts of what sexual and reproductive health included were discussed. Semi-structured conversational interviews were conducted via online video conferencing tools by the first author from March to November 2024. After obtaining verbal consent from participants, interviews were conducted in English, audio-recorded, and transcribed verbatim by a professional transcription service.

Analysis

In total, 75 survey responses were collected via Qualtrics™ and analyzed using Statistical Package for the Social Sciences (SPSS v29.0.1.0). Fourteen women participated in qualitative interviews, which were uploaded to NVivo software for management. As identified by Braun and Clarke (2021), the authors ensured data sufficiency through collection of rich data from interview participants. Accuracy of transcription was checked by listening and reading transcripts simultaneously, which was done repeatedly by (KO'R, EH, KP). This was a critical step in feminist research analysis as it ensures that women's voices were authentically reflected in the findings (Anderson & Jack, 1991). For this article, the data from interviews that align with the six sections of the survey described previously are presented. The combined approach of surveys and interviews provided a comprehensive assessment of the sexual and reproductive health of women who live with IBD. The data offers valuable insights into the interplay of participants' physical, mental, and emotional well-being on their sexuality.

Results

After excluding survey data ($n = 11$) that did not meet the inclusion criteria of woman, diagnosis of IBD, and living within Australia, 64 records were included in the analysis. Survey participants ranged in age from 19 to 59 years, with a mean age of 36 years and responses were anonymous. Geographically, most respondents resided in New South Wales/Australian Capital Territory (31.8%) and Victoria (28%) (see Table 2). Over half of the survey participants reported having CD (73.4%) with the remaining respondents reporting they had UC (26.6%) (see Table 3).

In the qualitative phase, 14 interviews with women who reported having CD ($n = 12$) and UC ($n = 2$) were conducted (see Table 3). Participants for whom pseudonyms are used to report findings ranged in age from 24 to 54 years, with a mean age of 34.1 years. The duration of interviews was

Table 2. Residence of survey and interview participants.

State/Territory	Survey	Interview
New South Wales/Australian Capital Territory	22	4
Victoria	18	4
South Australia	7	3
Western Australia	6	2
Queensland	10	1
Tasmania	1	0
Northern Territory	0	0

Table 3. Diagnosis of survey and interview participants.

Diagnosis	Survey	Interview
Crohn's Disease	47	12
Ulcerative Colitis	17	2

Table 4. Demographics—survey respondents.

Relationship status	*N* = 64	Living situation	*N* = 64	Employment	*N* = 64	Income past 12 months	*N* = 64
Married	22	Living with spouse / partner and children	21	Employed for wages	46	Less than $6,000	1
Defacto	22	Living with spouse / partner	20	Self employed	4	$6,001–$25,000	11
Single	19	Living in shared accommodation	7	Out of work and looking	4	$25,001–$60,000	13
Divorced	1	Living alone	5	A homemaker	2	$60,001–$100,000	26
		Living with parent/s	5	A student	5	> $100,000	9
		Living with parent/s and sibling/s	4	Retired	1	Don't know	1
		Living with children	2	Unable to work	2	Prefer not to answer	3

between 42 and 67 minutes with a mean duration of 53 minutes and a total of 12 hours and 51 minutes of data being recorded. At the time of interviews, most participants lived in New South Wales/Australian Capital Territory (34.3%) and Victoria (28.1%). No women from Tasmania or the Northern Territory volunteered to participate in an interview (see Table 2).

A majority of survey participants reported being married or in de facto relationships (68.7%). Most women reported living with their spouse, partner, and children or just their spouse or partner (64%). In terms of income, a majority of women were employed for wages (46%) and in the 12 months prior to completing the survey had incomes between $60,001 and $100,000 (40.6%) (see Table 4). This was followed by 20.3% of women earning between $25,001 and $60,000. A smaller proportion reported incomes exceeding $100,000 (14.1%), while lower-income groups earning less than $25,000 comprised 18.8% of the participants. This data highlights a diverse economic profile, with representation from all income groups reflecting variability in socioeconomic backgrounds among the participants.

Health Related Quality of Life

Sixty-three respondents completed all items on the SF-12 tool (Ware et al., 1995); one record was excluded due to a missing response to question 7. In this study, 81% of respondents reported scores below the midpoint of 50 in the MCS section, indicating poorer than average mental health. In contrast, physical health scores were slightly more favorable, though still concerning with 67% of participants scoring below the midpoint of 50 in the PCS section (see Figure 1).

The correlation between PCS and MCS scores was analyzed, with the best-fit trendline following a second-order polynomial ($y = 0.0172x^2 - 1.6116x + 74.368$, $R^2 = 0.0343$, $n = 63$). When converted to a bivariate correlation, the relationship was very weak ($r = 0.185$, $p = 0.1461$, $n = 63$), suggesting that physical and mental health scores were largely independent of one another (see Figure 2).

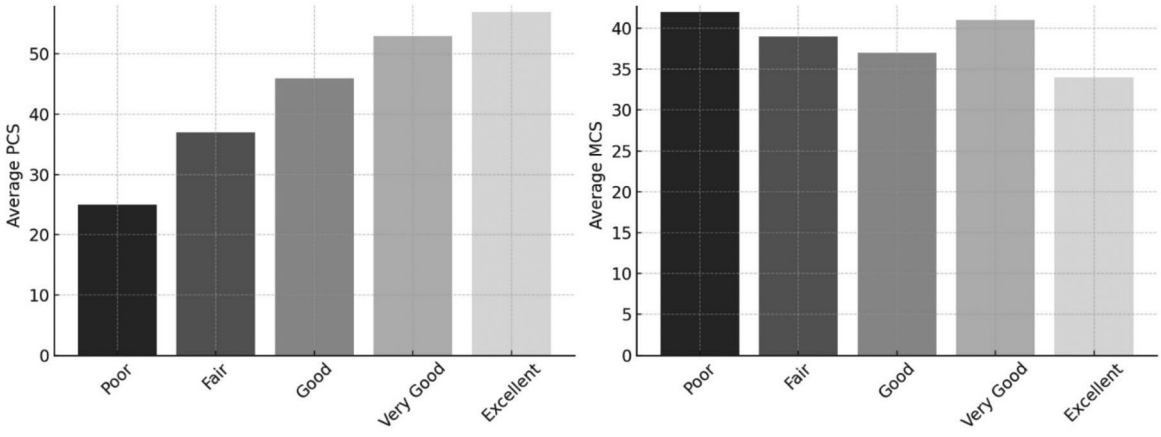

Figure 1. Physical and mental component scores.

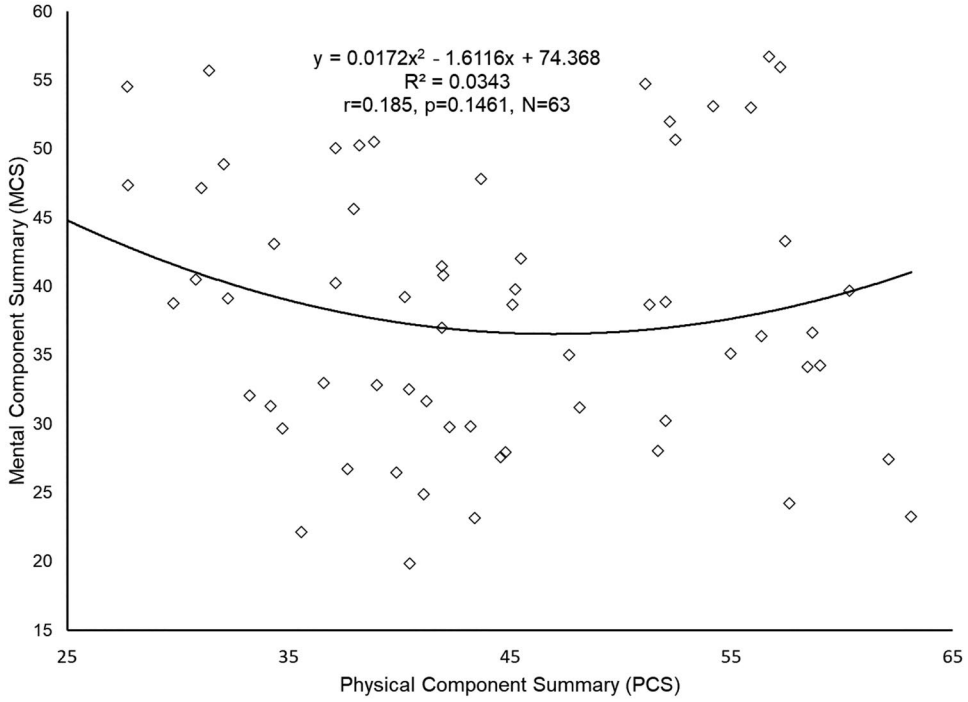

Figure 2. Correlation between SF-12 physical and mental component scores.

The findings reveal a nuanced relationship between PCS and MCS in women IBD. Women who rated their physical health as "Poor" or "Fair" often displayed higher mental health scores. Conversely, those who rated their physical health as "Excellent" or "Good" frequently reported lower mental health scores. As illustrated in Figure 1, this divergence highlights that emotional challenges can persist even when physical health is optimal.

The following quote provided by Carol highlights the importance of supporting physical and mental health simultaneously in women living with IBD. A holistic approach that considers both dimensions is essential for understanding overall quality of life.

> I talk about it, I guess, because it is such a big thing in my life, especially at the moment. A lot of other things in my life are impacted by it. It's like, oh, why don't you play sport anymore? It's because I was diagnosed with Crohn's disease and dealing with that. It is a little embarrassing to talk about, especially at university, at work. It's like, I can't come in today [laughs]. Disclosing that… There is a little bit of a mental block there, I suppose, with getting back into it. I'm not sure it's like, [laughs] I do want to, but it's a bit of a scary thing at the same time. (Carol, 25 years old, CD)

Reproductive Health

Little is documented in the broader research literature about changes to women's menstrual cycles when they have a diagnosis of IBD. More than half of the survey respondents in this study ($n = 34$; 53.1%) reported a change in their menstrual cycle.

The survey findings revealed diverse menstrual experiences, including changes in cycle regularity. Over half of the participants (53.1%) reported changes in their menstrual cycles following their diagnosis of IBD, although a notable portion (45.3%) described their cycles as regular without contraception or with contraception (23.4%). Tender or uncomfortable breasts were a common symptom, with many women indicating either definitely (28.1%) or sometimes (25.0%) experiencing discomfort. Abdominal cramps were reported by 37.5% of respondents as a definite characteristic of their menstrual cycle and 35.9% of respondents highlighting this was a feature sometimes. A bloated abdomen was another frequently reported concern, with almost half of the respondents (46.9%) identifying this as a definite issue. Heavy periods were a significant challenge, with 21.9% of survey respondents reporting them as definite characteristic and 25.0% of women reporting this occurred sometimes.

The open-ended responses provided by women at the end of the survey and from interviews underscore the substantial impact of IBD on menstrual health. Participants described exacerbation of IBD symptoms around their menstrual cycles even though many reported having regular cycles.

> I will say my Crohn's does get worse when I'm on my period in general, just the need to go to the loo [toilet] more with diarrhea. Not so much any stomach pains of period cramps, but specific to the Crohn's, it's just really the need to go to the toilet. I feel that urgency when I've got my period. I did actually bring that up to a couple of my doctors, and they said going on things like birth control pills might help, obviously, in stopping the period that would maybe then stop the flares every month [laughs]. I did try that for a couple of months, and I maybe noticed a slight improvement, but I don't know if it was just coincidental timing with something else because I did come off of them [contraceptive pill]. I didn't feel like the benefit outweighed all the other symptoms that come along with taking birth control pills. (Carol, 25 years old, CD)

Some women in this study reported having more intensified bowel related pain during their menstrual cycle, which they attributed to hormone fluctuations. The following response from a survey respondent highlights bowel related symptoms impacted them individually. "I know that my periods affect my bowel and I struggle on managing pains due to not having NSAIDS [Non-Steroidal Anti-Inflammatory Drugs] but they lacked an understanding of the physiological underpinning of why this was happening stating They were "unsure why the periods give me bowel symptomology." Productivity within the workplace was also affected yet repercussions of this were not always well understood by employers as highlighted in the following excerpt. "Probably just how hard it is to manage work if you're taking days off for pain that comes with menstruation but then also when colitis is flaring up but it's not something workplaces necessarily see as a disability" (Survey respondent).

Of the records that were included in the analysis, 25 women (39.1%) had been pregnant following a diagnosis of IBD with most pregnancies resulting in live births. The women's pregnancies that did not result in live births were due to miscarriage, still birth, or abortion. In total 26 women who responded to the survey reported having children, and this ranged from having one child to five children. The discrepancy with the pregnancy following IBD data indicates that one woman had a pregnancy before diagnosis.

Only one survey respondent elaborated on their experience of pregnancy and living with a diagnosis of IBD, highlighting that pregnancy was the catalyst to a flare-up of her otherwise well managed disease. The survey respondent explained that "in my experience my disease was well managed for nearly 20 years until I had a baby. Pregnancy really caused a lot of flare-ups for me."

A flare-up during pregnancy was also described by Diane following advice from her gastroenterologist to cease her medication. Diane explained that her first pregnancy resulted in a still birth. This was attributed to poor placental growth due to uncontrolled disease in the first trimester. Her description highlights advice provided by health professionals did not always align with best practice guidelines.

> So I fell pregnant. So I was like, okay, stop my medication, like I was told to do. Then yeah, consequently got a flare… throughout the whole pregnancy it was very much, like, the care plan was all over the place. (Diane, 34 years old, CD)

Conversely, Pari laughed joyfully as she explained that her disease had settled during pregnancy, highlighting the vastly different experiences of pregnancy. Pari who at the time of interview was 54 years old reflected that during her pregnancies, "I was great. I always went into remission so I loved being pregnant. It was like, wow, this is amazing. This is what normal people are like" (Pari, 54 years old, CD).

Sam highlighted that her experience of becoming pregnant was made more complex by a constellation of diagnoses that impacted her fertility.

> So I've been given a diagnosis of PCOS [Polycystic Ovary Syndrome]… then I got a diagnosis of adenomyosis not long after that. Then I obviously got diagnosed with Crohn's disease. I was struggling with infertility, went through IVF [in vitro fertilization] unsuccessfully and then after that… I actually had a baby. (Sam, 45 years old, CD)

More than half of the 63 women who completed the reproductive health screening section of the survey related to cervical screening ($n = 47$; 74.6%) had a pap-smear test within the previous five years. Conversely more than half of the 64 respondents ($n = 38$; 59.4%) reported that they did not complete a self-examination of their breasts each month and half ($n = 32$; 50.0%) had not had a breast examination by a physician or a nurse.

As highlighted from the survey, many women who participated in interviews reported feeling their general practitioners (GP) were very proactive in regard to cervical screening. Kelly highlighted that this was an important part of her care given the complexity related to anatomical changes following a colectomy.

> My GP's amazing, she's on top of everything. Unfortunately with all my scar tissue from fistulas, they're unable to do the cervical screening now in the rooms. It normally gets done under anaesthetic because my uterus has moved… my cervix has tipped forward because my abdomen, and everything is so empty. (Kelly, 36 years old, CD)

Pari and Belinda both indicated that they had maintained cervical cancer screening; however, as also identified on the survey, self-examination of their breasts was not something they routinely did. Nicole who had CD, explained that at 23 years of age, reproductive health screening with a doctor was not something she had done yet. Nicole explained that cervical screening and breast checks were "definitely always at the forefront of my mind." However, she identified factors such as "just even getting in with GP's is, it's quite difficult, especially after COVID" were barriers to actioning her responsible, health aware intentions.

Sexual Satisfaction

Of the 64 survey respondents, 56 women completed the sexual satisfaction section of the survey. In this study, there were a range of scores from 4 to 24 reported by women. Over half of the respondents to this section of the survey ($n = 30$; 53.6%) scored from 4 to the midpoint of 15 with the remaining respondents ($n = 26$; 46.4%) scoring 16 to 24, which indicated a higher level of sexual dissatisfaction (see Table 5).

Open-ended responses shared at the end of the survey and in interviews provide further context about factors that negatively impacted sexual satisfaction. Participants below described the physical and psychological challenges such as pain during flare-ups, perianal fistulas, limited knowledge, and self-consciousness negatively impacting sexual intimacy.

> …Also sex life feels less comfortable because of the disease, often feel full, like I need the bathroom but then can't go so don't really want to have sex if I feel like I need to go to the toilet to empty my bowels. (Survey respondent)

Table 5. Sexual Satisfaction Scale.

Sexual satisfaction score	$N = 64$	(%)
4	10	15.6
5	2	3.1
7	2	3.1
8	6	9.4
9	1	1.6
10	2	3.1
11	2	3.1
12	5	7.8
13	3	4.7
14	1	1.6
15	4	6.3
16	3	4.7
18	2	3.1
19	4	6.3
20	3	4.7
21	1	1.6
22	1	1.6
23	1	1.6
24	3	4.7
Missing Data	8	12.5

> Like can you even have sex when you have a seton? I don't know. Do I want to know the answer to that? No. Because I know how much it hurts and pains, and then someone has to do the dressing for it. Which is like a humiliation max out… Then you're meant to find this person attractive? (Maggie, 30 years old, CD)

The example of Maggie raising questions in the above quote shines a light on the internal tension she has about her sexual partner also providing intimate care to manage her seton. The underlying tone during the interview revealed her worry that her partner would no longer see her as desirable.

The following excerpts provided by Nicole and Belinda highlight additional factors that impacted negatively on sexual intimacy. Women in this study believed anal skin tags that they considered to be unsightly and a body that they did not have full control over made them less desirable. The cascade of IBD symptoms and feeling less desirable also left many women in this study feeling desireless.

> My disease was so severe when I was diagnosed, I actually had really large skin tags across my anus. They hadn't been removed because they weren't hurting or harming, they weren't bleeding or anything; it wasn't a priority. So when I was, I think 16, I actually asked for them to be removed because I didn't want to explore any relationships with people because I didn't want them to see that or anything. So I think there was a tough period where my disease—not even it's—it wasn't as active, but just the previous issues from it were sort of preventing me from wanting to be in relationships with people, which is quite an important part of that time of your life. You're exploring that, so yeah. (Nicole, 23 years old, CD)

> Yeah, definitely, and also a bit of leakage. So, and that too, with having partners and things, that's—you don't feel very sexy when you have to keep going to the bathroom, or—yes, something's leaking out of your rear end, or you're afraid that's going to happen. There's a real anxiety around that. (Belinda, 41 years old, CD)

These findings highlight the complex interplay between IBD symptoms, self-perception, and sexuality.

IBD Pregnancy Knowledge

A total of 60 women completed the pregnancy knowledge section of the survey, and the mean score was 8.7, which sits at the low end of the adequate IBD related pregnancy knowledge range. Very few women ($n = 5$; 7.8%) had very good IBD related pregnancy knowledge.

The following quotes relate to women's fertility concerns. Open-ended responses from the survey showed that consistent information about fertility was at times difficult to obtain with one survey respondent reporting "information online can be contradictory." This added an additional layer of anxiety as she highlighted that she was worried that past decisions related to her health may have implications on her fertility further down the track stating: "decisions I made for my health will affect my ability to have children." Another survey respondent said that soon after their diagnosis of IBD they "received a lot of misinformation about an inability to conceive." The survey respondent explained the negative impact this had on their mental well-being, sharing that this caused "significant

Table 6. CCPKnow scale scores.

CCPKnow score	$N = 64$	(%)
Poor (0–7)	19	29.7
Adequate (8–10)	19	29.7
Good (11–13)	17	26.6
Very Good (≥ 14)	5	7.8
Missing Data	4	6.2

Table 7. Rosenberg self-esteem scale scores.

Self-esteem scale	$N = 64$	(%)
Low self esteem (0–14)	14	23.7
Normal self esteem (15–24)	45	76.2
High self esteem (25–30)	0	0
Missing data	5	

anxiety and depression." The same survey respondent explained that it took them a protracted period to gather correct information, stating "thankfully I now know different. Took 13 years to learn otherwise."

The responses above and below highlight that there is a substantial knowledge gap regarding fertility related issues among women with IBD, which aligns with the Crohn's and Colitis Pregnancy Knowledge (CCPKnow) scores collected in the survey (see Table 6). Additionally, women's responses highlight that clinicians' knowledge regarding fertility and best practice IBD pregnancy management may also be lacking.

> How pregnancy is for people with Crohn's? Do they require a C-section? Are they able to give a vaginal birth? I know some drugs they recommend not taking if you're planning to get pregnant. I'm not sure what one's exactly. (Carol, 25 years old, CD)

Self Esteem and Body Image

Of the 64 surveys included in the analysis, only 59 respondents completed the Rosenberg's Self-Esteem Scale (RSES). The results for the completed the RSES showed a relatively narrow range of scorers from 12 to 19 with the mean self-esteem score being 15.7 (see Table 7), which is on the lowest end of the normal self-esteem score. A majority of women (76.2%) who completed RSES reported self-esteem within normal rage as can be seen in Table 7; however, 19 was the highest score, which is only the mid-point of the normal self-esteem range. There were no women who participated in this study with a high self-esteem score.

Of the 64 surveys included in the analysis, there were 58 responses to this question. In total, 42 women (65.6%) reported perceiving their bodies looked different compared to before their diagnosis of IBD, while 16 women (25%) indicated a neutral response. Women were also asked if they were satisfied with their physical appearance. Of the 64 records analyzed, 59 responses to this question were recorded. Almost half ($n = 29$; 49.2%) of the women who responded to this question reported that no, they were not satisfied with their physical appearance. A total of 10 women (16.9%) said that yes, they were satisfied with their physical appearance, and 20 women (33.9%) offered neutral responses. The following quotes elaborate on the profound impact IBD had on women's self-esteem and body image. This impact was related to anticipatory fear of surgery. One survey respondent stated "I constantly fear the thought of surgery and seeming weird to everyone else." This response emphasized that surgery may result in a deviation from what are considered normal societal expectations related to physical appearance.

Pari explained the juxtaposition of the lived reality of surgery. In one sense, her surgery was life-saving, but the excoriation from fecal matter and the worry about leaking in front of people negatively impacted her self-confidence:

> I looked so sick because I'd lost so much weight. Like, you know, you don't look healthy when you lose that type of weight, so I was just gaunt. I went down to, I think, about 50 kilograms or something. I lost all my confidence. I'm quite a confident person, I could easily lecture in front of 200 people, and it wouldn't

> bother me at all… Because I never knew when this stupid ileostomy was going to leak because all of a sudden, I'd just be thinking it's leaking. I could feel like it burning my skin. It wasn't pleasant and it wasn't pleasant for people. I didn't want people to see that or be near me. (Pari, 54 years old, CD)

Fluctuating weight due to periods of active disease and remission was identified by women in this study. In the excerpt above, Pari identified that she did not look healthy due to rapid weight loss. Carol below identified that her nutritional state impacted the health of her hair and skin, which may have also been compounded by side effects from medications:

> I'm not sure if my hair was thinner just because of the Crohn's because I was quite malnourished and I was extremely anaemic. My hair was a lot thinner. I remember just going through that and then pulling out clumps, but I'm also aware some of the medications can… cause you to lose some hair sometimes. The period that I was on the steroids, my skin texture went a bit funny. I actually started to get an increase of facial hair, which I was very surprised about… It was a bit of an unexpected symptom… Oh [felt], very self-conscious. I'm like, oh gosh, I'm going to have to start getting my face waxed. (Carol, 25 years old, CD).

Danielle explained that prior to her diagnosis of CD she already experienced self-consciousness about her body size. The need for a seton drain for a perianal fistula extended this self-consciousness further, to include her genitalia:

> Growing up a bigger girl, I've been self-conscious about just about every part of my body before. Never, never my genitals, so it was—oh, it's been a really hard couple of weeks since having this diagnosis and since having the seton. I haven't been sexually active since. (Danielle, 24 years old, CD)

These examples all highlight that socialized norms of what is considered healthy, attractive, or normal influence self-perception and thus self-esteem for women who live with IBD.

Discussion

The aim of this study was to explore the sexual and reproductive health of women who live with IBD in Australia using an online survey and interviews. Participants shared insights into the deleterious impact IBD symptoms have on their sexual well-being, which aligns with findings from Fourie et al. (2024) and Ma et al. (2020). Pelvic pain due to the inflammatory nature of IBD and fistula formation in participants who had a diagnosis of CD was identified in this study as a significant factor that impacted upon sexuality. While the relationship between physical and mental health using the SF-12 in this study was weak, we argue that there is a nuanced relationship. As identified by Howard (2003), there are several conditions that contribute to chronic pelvic pain in women, with IBD being one of these. The relapsing remitting nature of IBD and the chronicity of living with pain led to invasive surgical procedures such as placement of seton drains, bowel resection or stoma formation for some women this this study. Wall et al. (2024) highlights that chronic pelvic pain and surgical procedures to treat pain have the potential to impact on a person's mental health and may even cause post-traumatic stress. This may help to explain the nuanced relationship between physical and mental health components of the SF-12. After a participants' physical health had returned to some level of equilibrium following a flare-up of their disease participants may continue to experience a negative impact on their mental health. The impact of pain along with delay, misinformation and contradictory advice in relation to medications and pregnancy as highlighted by some women in this study may further contribute to negative experiences (Trotter-Ross et al. 2023).

Many women who participated in this study were in their reproductive years and a gap in knowledge regarding reproductive health and family planning was evident. These findings are not unique to our study and align with what Toomey and Waldron (2013) reported. The fact that this knowledge gap is evident in studies that are more than ten years apart emphasizes the need to ensure equitable access to clear, evidence-based guidelines that address fertility, preconception counseling, medication safety, and multidisciplinary antenatal and postnatal care such as those compiled by Godney et al. (2023). Additionally, women in this study identified a link between hormones and intensified gastrointestinal symptoms, which is also reported by Walker and Gaidos (2019). These hormonal variations that increased feelings of fecal urgency, flatulence,

abdominal pain, and increased blood loss during menstruation reported in this study must be considered in the ongoing care of women who live with IBD. Drawing attention to women's gaps in knowledge, and access issues is a critical element of feminist research as it highlights an historical disparity related to women's health research that Patwardhan et al. (2024) identify continues to be reflected in women's disease burden.

Wall et al. (2024) explained that little research has been done that explores chronic pelvic pain; however, this is growing in relation to women who live with endometriosis (Armour et al., 2023; Netzl et al., 2022; Wall et al., 2024). As previously stated, Howard (2003) outlined that IBD is one of many conditions that can result in chronic pelvic pain. Some women in this study reported living with IBD in addition to adhesions as a result of surgeries, endometriosis, polycystic ovary syndrome, and adenomyosis, all of which Howard (2003) identifies may contribute to more complex pelvic pain. Chronic pelvic pain along with increased diarrhea and flatulence when menstruating, concerns about fecal incontinence during sexual intercourse, visible seton drains, scarring, and skin tags were reported by various women in this study. Weight loss and weight gain, thinning hair, and the growth of facial hair were also outlined. All these factors were identified by participants to impact negatively on self-esteem, which Elias et al. (2025) and Knowles et al. (2013) found can also impact on intimate relationships.

It is recognized within the literature that there is a need to increase research that specifically focuses on women's health. Further to this, research that considers women's sexual and reproductive health requires further exploration. As explained by Chrisler et al. (2020), such research is critical to raise consciousness in an effort to promote well-being. While there is research available, it is often considered through a lens of dysfunction (Boudiaf et al., 2021; Shmidt et al., 2019). This focus on dysfunction is at odds with the World Health Organization (WHO) (2015) definition of sexual health, which is defined as "a state of physical, emotional, mental and social wellbeing in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity" (p. 5). The WHO highlight that there have been various iterations of this working definition over several years, which they critique as not always being inclusive of the broader dimensions of sexuality that extend beyond reproduction. The WHO (2015) highlight that, to ensure the promotion of sexual health and human rights, the definition of sexual health above must also be considered in conjunction with the following definition of sexuality described as: "a central aspect of being human throughout life; it encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors" (p. 5). These definitions are an important underpinning when considering the findings from this study. Findings from this study highlight that clinicians must think well beyond conversations that are limited to fertility and reproduction to ensure discussions are comprehensive and truly reflect the broader aspects of sexuality as outlined in the WHO (2015) definition.

Conclusion

This study provides important insights into the sexual and reproductive well-being of Australian women who live with IBD, highlighting critical gaps in knowledge, communication, and care delivery. The authors caution against the generalizability of findings given the focus on the Australian context. However, the findings do draw attention to the importance of contextual factors, emphasizing the need for holistic, person-centred approaches that address the physical, psychological, and social dimensions of living with chronic conditions for women globally. Evidence-based education, proactive communication by healthcare providers, and integrated care strategies are essential to improve outcomes and to empower women who live with IBD. By addressing these unmet needs and implementing targeted interventions, healthcare systems can enhance quality of care by incorporating the concept of sexual well-being into models of care.

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No potential conflict of interest was reported by the author(s).

Ethical Approval

Ethical approval was through Western Sydney University H15913.

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Data Availability Statement

The participants of this study did not give written consent for their data to be shared publicly due to the sensitive nature of the research.

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