

Perspectives on Contraception, Pregnancy, and Reproductive Health Counseling from Young Women With Inflammatory Bowel Disease

Erica J. Brenner, MD, MSCR^{*}, Mary E. Grewe, MPH[†], Catalina Berenblum Tobi, MD[‡],
Amy G. Bryant, MD, MSCR[§], Marla C. Dubinsky, MD[¶], Xian Zhang, PhD^{*},
Millie D. Long, MD, MPH^{||}, Michael D. Kappelman, MD, MPH^{*}, and Mara Buchbinder, PhD^{**}

^{*}Division of Pediatric Gastroenterology, Department of Pediatrics, Center for Gastrointestinal Biology and Disease, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

[†]North Carolina Translational and Clinical Sciences Institute, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

[‡]Department of Pediatrics, Boston Children's Hospital, Harvard Medical School, Boston, MA, USA

[§]Department of Obstetrics and Gynecology, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

[¶]Dr. Henry D. Janowitz Division of Gastroenterology, Department of Pediatrics, Icahn School of Medicine at Mount Sinai, New York, NY, USA

^{||}Division of Gastroenterology and Hepatology, Department of Medicine, Multidisciplinary Center for Inflammatory Bowel Diseases, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

^{**}Department of Social Medicine, Center for Bioethics, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Address correspondence to: Erica J. Brenner, MD, MSCR, 333 S. Columbia St., 247 MacNider Hall, CB# 7229, Chapel Hill, NC 27599, USA (Erica.Brenner@unchealth.unc.edu). Tel: 919-962-4416

Background/Aims: Active inflammatory bowel disease (IBD) increases the risk of pregnancy complications and contraceptive side effects, and contraceptive use may impact the clinical course of IBD. Although young people are at elevated risk for unintended pregnancy, those with IBD receive minimal disease-specific contraceptive guidance. We characterized perspectives and preferences on contraception and reproductive health counseling from young *cis*-women with IBD.

Methods: We conducted 60-min semi-structured interviews with *cis*-women with IBD ages 18-30 (recruited nationwide and from North Carolina IBD clinics; February–June 2023). Interview guides included questions about reproductive health and preferences for receiving reproductive health information. Audio-recordings were professionally transcribed and coded using an inductive, thematic approach and Dedoose software.

Results: Participants included 30 *cis*-women with IBD (ages 18-30, 77% White, 7% Hispanic, and 55% Crohn's disease). Some participants shared that IBD increased their menstrual symptom burden, prompting contraceptive use to control menses. Participants discussed the impact of IBD on their contraceptive decision-making, including concerns regarding blood clots. For a participant subset, IBD did not impact contraceptive decision-making. Participants discussed how IBD impacted their perspectives on childbearing, including concerns about IBD heritability, infertility, and peripartum IBD flares. Participants wanted their gastroenterology provider to proactively address reproductive health, provide appropriate resources, and coordinate care with reproductive health providers.

Conclusions: Young *cis*-women with IBD may have IBD-specific concerns about contraceptives, pregnancy, and menstrual symptoms and desire better IBD-related reproductive health counseling. Inflammatory bowel disease providers can improve reproductive health counseling by proactively addressing IBD-specific reproductive health questions, providing reproductive health resources, and coordinating care.

LAY SUMMARY

Young women with inflammatory bowel disease (IBD) may have IBD-specific concerns about contraceptives, pregnancy, and menstrual symptoms and desire better IBD-related reproductive health counseling. Inflammatory bowel disease providers can improve reproductive health counseling by addressing reproductive health questions, providing resources, and coordinating reproductive health care.

Key Words: inflammatory bowel disease, reproductive health, contraception

Introduction

People with inflammatory bowel disease (IBD) capable of pregnancy face an increased risk of pregnancy complications and contraceptive side effects such as thromboembolism.¹⁻³ Moreover, IBD often requires treatment with teratogenic medications.⁴ Yet *cisgender* (*cis*)-women with IBD are less likely to use contraceptives than those without IBD.⁵ Inflammatory bowel disease heavily influences family planning

decisions: Compared to *cis*-women without IBD, those with IBD are more likely to choose not to have children.^{6,7} Given the substantial impact of IBD on reproductive health, leading gastroenterology organizations recommend that people with IBD capable of pregnancy receive IBD-specific reproductive health counseling.^{8,9}

Adolescent and young adults with IBD who are capable of pregnancy represent an important target for such

Received for publication: September 9, 2024. Editorial Decision: November 27, 2024

© The Author(s) 2024. Published by Oxford University Press on behalf of Crohn's & Colitis Foundation.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-Non-Commercial License (<https://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

For commercial re-use, please contact reprints@oup.com for reprints and translation rights for reprints. All other permissions can be obtained through our RightsLink service via the Permissions link on the article page on our site—for further information please contact journals.permissions@oup.com.

reproductive counseling. The American College of Obstetrics and Gynecologists recommends that contraceptive counseling take place during adolescence, ideally before a patient becomes sexually active.¹⁰ Moreover, high-risk sexual activity occurs more frequently among young adults than older individuals.^{11,12} Compared to menstruating people over age 25, menstruating adolescents and young adults are more likely to have an unintended pregnancy, inadequate access to reproductive healthcare, and contraception misconceptions.^{13–16} As such, researchers studying reproductive health in other chronic diseases have analyzed adolescent and young adults capable of pregnancy as a distinct population and used the findings to create tailored reproductive health recommendations.^{17–24} Adolescent and young adult *cis*-women with chronic diseases such as cystic fibrosis prefer disease-specific reproductive health counseling to come directly from their subspecialist.^{24,25} While *cis*-women with IBD may have a similar perspective,^{6,7} this question remains under-explored, particularly in the young population.

Currently, menstruating adolescents and young adults with IBD tend to receive minimal disease-specific guidance on reproductive health.^{7,22} Inflammatory bowel disease physicians and patients with IBD often feel uncomfortable discussing reproductive health and consequently avoid the topic.^{7,26} Moreover, while better clinical guidelines and shared decision aids would facilitate counseling for young people with chronic disease,^{18,24,27} such guidelines and tools have not yet been developed for IBD. Notably, pediatric IBD preventive and transitional care resources do not even *mention* contraception,^{28–31} and adult IBD contraceptive recommendations fail to address the unique needs of young people capable of pregnancy.^{9,32} Furthermore, young people with IBD may not follow IBD-specific reproductive health recommendations. Although the American Gastroenterological Association (AGA) recommends avoiding estrogen-based contraceptives due to a risk of blood clots and endorses long-acting reversible contraceptives (LARCs) as first-line for menstruating people with IBD,⁹ the majority of those ages 15–25 in one US-based study used estrogen-based methods (72%), and only 18% used LARCs.³³ While the Center for Disease Control (CDC) Medical Eligibility Criteria provides a more nuanced recommendation than the AGA by stating that the benefits of estrogen-based contraceptives generally outweigh the risks for people with mild IBD and no other risk factors for blood clots, these guidelines also caution against use of estrogen-based methods in the setting of thromboembolic risk factors.³⁴ Given these safety concerns and the popularity of estrogen-based contraceptives among young menstruating people with IBD, IBD providers need to better understand patient perspectives on these methods and identify knowledge gaps to engage in effective shared decision-making with their patients.

We sought to understand the influence of having IBD on young *cis*-women's decision-making about reproductive health and their reproductive health counseling preferences by interviewing young *cis*-women with IBD regarding their perspectives on reproductive health and IBD and their preferences for IBD-specific reproductive health counseling. We explored how *cis*-women factor their IBD into reproductive-health decision-making and assessed opportunities to improve reproductive health care for this population.

Materials and Methods

Design

We used a qualitative descriptive methodological approach³⁵ to design the study. Our team consulted with experts from the Inclusive Science Team at the North Carolina Translational and Clinical Sciences Institute³⁶ to discuss inclusion criteria for the study. Our research team concluded that people with IBD who are capable of pregnancy but are gender diverse may have unique perspectives that merit separate evaluation from *cis*-women with IBD; Accordingly, we decided to include only *cis*-women (those who were assigned female at birth and identify as a woman; referred to as “women” henceforth) in the present study. We invited United States (US) women ages 18–30 who developed Crohn's disease, ulcerative colitis, or IBD unspecified before the age of 25 to participate in semi-structured interviews. As our study focused on the adolescent and young adult population, defined as those aged 18–25 per previous work,^{37,38} we recruited women throughout this age range plus a cohort aged 26–30 who could reflect on their experiences and perceptions during ages 18–25. Eligible participants endorsed at least one of the following: current contraceptive use, history of contraceptive use, or thinking about using contraception in the future. Our recruitment scripts included the terms “contraception” and “birth control.” If questions arose, we told prospective participants that both hormonal and nonhormonal methods would meet criteria.

We assembled a Patient Advisory Board (PAB) to provide input on study design and data collection procedures. We recruited the PAB through the Improve Care Now Patient Advisory Council. The PAB included 3 young women with IBD representing late adolescence, early 20s, and late 20s. All PAB members identify as White race and one of them is of Hispanic/Latine ethnicity. One PAB member was from North Carolina and 2 were from California. All of them had previously worked with diverse groups of young people with IBD through advocacy work, which allowed them to provide insight into designing a patient-centered study for diverse populations. Patient Advisory Board members provided input into all facets of study design and content of all patient-facing study materials. The PAB met with the research team on a bi-monthly basis throughout the study via a remote teleconferencing platform and communicated through email between meetings from December 2021 through October 2024. One of the PAB members coded and analyzed interview transcripts and critically edited the manuscript. The study was approved by the Internal Review Board at the University of North Carolina at Chapel Hill.

Data Collection

We recruited women with IBD ages 18–30 from the University of North Carolina (UNC) adult and pediatric IBD clinics and from the IBD Partners patient-powered research network³⁹ and the ICN network.⁴⁰ Our *a. priori* goal was to recruit half of the participants from the UNC clinics and the other half nationwide from the IBD Partners and ICN networks. This recruitment strategy was chosen to enhance study diversity, as the UNC clinic population includes robust racial, ethnic, and socioeconomic diversity, while the patient-powered research networks include patients across the United States. Using a purposive sampling approach, we continued recruitment until: (1) the study sample approximated the racial and ethnic

composition of the US IBD population, of whom 79% identify as White race and 13% identify as Hispanic ethnicity,⁴¹ and (2) we reached thematic saturation.

We conducted semi-structured interviews lasting approximately 60 minutes each. The interviews were conducted remotely in a private space by E.B., a female pediatric gastroenterologist at UNC, and M.G., an experienced female qualitative researcher. M.G. interviewed all participants receiving care in North Carolina (NC) and E.B. interviewed participants outside of NC. While we offered an in-person option for participants in NC, all participants opted for a virtual interview. In consultation with the PAB and a reproductive health expert, we developed two interview guides: one for 18-25-year-old participants, which asked them to reflect on their current experiences, and another for 26-30-year-old participants, asking them to reflect on their experiences when they were ages 18-25. Both guides assessed experiences and preferences related to contraception, reproductive health, and reproductive health counseling. (see [Supplementary Data Content 1](#) and [2](#) for the interview guides.) Interviews were audio-recorded and then professionally transcribed and de-identified. We then quality-checked the transcripts and uploaded them to Dedoose qualitative analysis software (v9.0.17, SocioCultural Research Consultants, LLC, 2021). Interviewers collected demographic and reproductive health history information via a verbal questionnaire at the conclusion of each interview. Participants were provided a \$35 gift card for their participation.

Participants were encouraged to discuss health questions or concerns with their provider(s). If misconceptions were noted during the interview, we provided links to evidence-based online reproductive health resources, from sources including the Crohn's and Colitis Foundation⁴² and the Pregnancy in IBD and Neonatal Outcomes (PIANO) study website.⁴³

Data Analysis/Statistical Considerations

We calculated summary statistics including numbers and percentages of participant demographics, IBD history, and reproductive health history, both overall and stratified by age group (18-25 and 26-30 years). Three team members (E.B., M.G., and C.B.T.) used a deductive and inductive, thematic approach to code and analyze interview transcripts, with guidance from M.B. We created an initial codebook based on preliminary memos generated by interviewers during data collection, the interview guide, and study aims. During an initial coding period, the coding dictionary was refined iteratively as coders suggested additional codes and clarified code definitions. During this period, 4 transcripts were coded by all 3 analysts to establish intercoder reliability and shared understanding of the codes. Once coding was consistent across coders, we divided the remaining transcripts ($n = 26$) among the team members for independent coding. Any remaining uncertainties about coding applications were discussed collaboratively and resolved. After coding, we reviewed code co-occurrence tables and code reports to identify and describe key themes and relationships between themes.

Ethical Considerations

We obtained verbal consent from participants. Prior to enrollment, we provided each potential participant with a research information sheet explaining the purpose of the

study, study procedures, possible risks of participating, and procedures undertaken to minimize risk. Personal identifiers of participants were removed from interview transcripts. Identifiers obtained for the purposes of recruitment were stored separately from the research data and were not linked to the research data. The study was approved by the University of North Carolina Institutional Review Board.

Results

Participants included 30 women with IBD from 13 states; 57% (17/30) were aged 18-25. Participants self-identified as Hispanic (7%) and as Asian (7%), Black (17%), and/or White (77%). Fifty-five percent of participants had Crohn's disease, while the remainder had ulcerative colitis or IBD unspecified. Forty-three percent of the sample saw a pediatric IBD provider during ages 18-25. The most common contraceptive methods used during ages 18-25 were condoms (57%), the combined oral contraceptive pill (50%), and the intrauterine device (IUD; 27%) ([Table 1](#)).

We identified 3 overarching themes: perspectives on contraceptives and IBD, perspectives on pregnancy and IBD, and communication preferences ([Figure 1](#)). These themes are elaborated below with illustrative quotations (see [Supplementary Data Content 3](#) for additional quotations).

Theme 1: Perspectives on Contraceptives and IBD IBD can increase menstrual symptom burden and thus prompt contraceptive use

Many participants endorsed increased gastrointestinal symptoms and/or menstrual symptoms during menses, along with frustration at the lack of treatments to alleviate menstrual symptoms, given their IBD. One participant explained,

We tried treating the nausea. We tried treating the pain. At some point—I know I can't take NSAIDs—there's only so much Extra Strength Tylenol can do for you, and the answer is not a lot. (24-year-old participant)

This participant, who ultimately decided to have an IUD placed for her symptoms, shared how it gave her peace of mind:

I think it's also just the anxiety relief, again, about is this a flare? Is this not a flare? Where is the blood coming from? Because now I don't get periods, and so I know if there's blood, there's only one place it's coming from, which is—it's a relief. (24-year-old participant)

Other respondents reported overlap between their menstrual and IBD symptoms. A participant with a fistula from Crohn's disease recalled that

...during my cycle, when I have my period, the fistula gets very irritated, and that causes issues even with my stomach. There's more cramping than just the normal period cramps. (21-year-old participant)

She added that she wished her gastroenterologist had explained why and how these menstrual symptoms occurred.

Others discussed the ways in which these overlapping symptoms factored into their contraceptive decision-making.

Table 1. Demographics, inflammatory bowel disease disease characteristics, and reproductive health characteristics of study population.

	Participants aged 18-25 (N, %)		Participants aged 26-30 (N, %)		All participants (N, %)	
Number	17	56.7%	13	43.3%	30	–
Number of states represented	8	–	6	–	13	–
Race ^a						
Asian	2	11.8%	0	0.0%	2	6.7%
Black or African American	1	5.9%	4	30.8%	5	16.7%
White	14	82.4%	9	69.2%	23	76.7%
Ethnicity						
Hispanic/Latina/Latine	1	5.9%	1	7.7%	2	6.7%
IBD subtype						
Crohn's disease	11	64.7%	5	38.5%	16	53.3%
Ulcerative colitis	5	29.4%	5	38.5%	10	33.3%
IBD unspecified	1	5.9%	3	23.1%	4	13.3%
Overall IBD severity						
In remission	0	0.0%	1	7.7%	1	3.3%
Mild	4	23.5%	3	23.1%	7	23.3%
Moderate	8	47.1%	5	38.5%	13	43.3%
Severe	4	23.5%	3	23.1%	7	23.3%
Unsure	1	5.9%	1	7.7%	2	6.7%
Current IBD medications						
Antibiotics	0	0.0%	0	0.0%	0	0.0%
Mesalamine	1	5.9%	2	15.4%	3	10.0%
Biologic therapy	13	76.5%	6	46.2%	19	63.3%
Corticosteroids	3	17.6%	1	7.7%	4	13.3%
Immunomodulator ^b	3	17.6%	4	30.8%	7	23.3%
Tofacitinib or upadacitinib	1	5.9%	0	0.0%	1	3.3%
Ozanimod	0	0.0%	1	7.7%	1	3.3%
Other	4	23.5%	3	23.1%	7	23.3%
None	1	5.9%	1	7.7%	2	6.7%
Unsure	0	0.0%	1	7.7%	1	3.3%
Type of provider seen for IBD care during ages 18-25						
Pediatric gastroenterologist	7	41.2%	3	23.1%	10	33.3%
Pediatric advanced practice provider	1	5.9%	2	15.4%	3	10.0%
Other (includes adult providers)	9	53.0%	8	61.5%	17	56.7%
IBD provider setting						
University setting	16	94.1%	5	38.5%	21	70.0%
Private practice	1	5.9%	7	53.8%	8	26.7%
Other	0	0.0%	1	7.7%	1	3.3%
Sexual orientation ^a						
Asexual	0	0.0%	1	7.7%	1	3.3%
Bisexual	1	5.9%	4	30.8%	5	16.7%
Straight	15	88.2%	5	38.5%	20	66.7%
Pansexual	0	0.0%	1	7.7%	1	3.3%
Questioning or unsure	1	5.9%	0	0.0%	1	3.3%
Same-gender loving	0	0.0%	1	7.7%	1	3.3%
Choose not to answer	0	0.0%	1	7.7%	1	3.3%
History of sexual intercourse with a male partner						
Yes	15	88.2%	11	84.6%	26	86.7%
No	2	11.8%	1	7.7%	3	10.0%
Choose not to answer	0	0.0%	1	7.7%	1	3.3%
Contraceptive method(s) used during ages 18-25 ^{a,c}						
Abstinence	1	5.9%	1	7.7%	2	6.7%
Combined oral contraceptive pill	6	35.3%	9	69.2%	15	50.0%

Table 1. Continued

	Participants aged 18-25 (N, %)		Participants aged 26-30 (N, %)		All participants (N, %)	
Condoms	10	58.8%	7	53.8%	17	56.7%
Contraceptive injection	2	11.8%	3	23.1%	5	16.7%
Intrauterine device (IUD)	3	17.6%	5	38.5%	8	26.7%
Progestin-only pill	1	5.9%	3	23.1%	4	13.3%
Withdrawal	3	17.6%	4	30.8%	7	23.3%
No method	1	5.9%	0	0.0%	1	3.3%
Choose not to answer	0	0.0%	1	7.7%	1	3.3%

^aThe following multiple-choice responses were omitted from the table because no participant chose them: Race: American Indian/Native Alaskan, Native Hawaiian/Pacific Islander, Other, Unsure; Sexual orientation: Gay, Lesbian, Queer, Other; Contraceptive method(s): Implant, Patch, Ring, Rhythm method, Sterilization, Other.

^bImmunomodulator includes methotrexate, 6-mercaptopurine, or azathioprine.

^cParticipants were asked to choose as many methods as relevant.

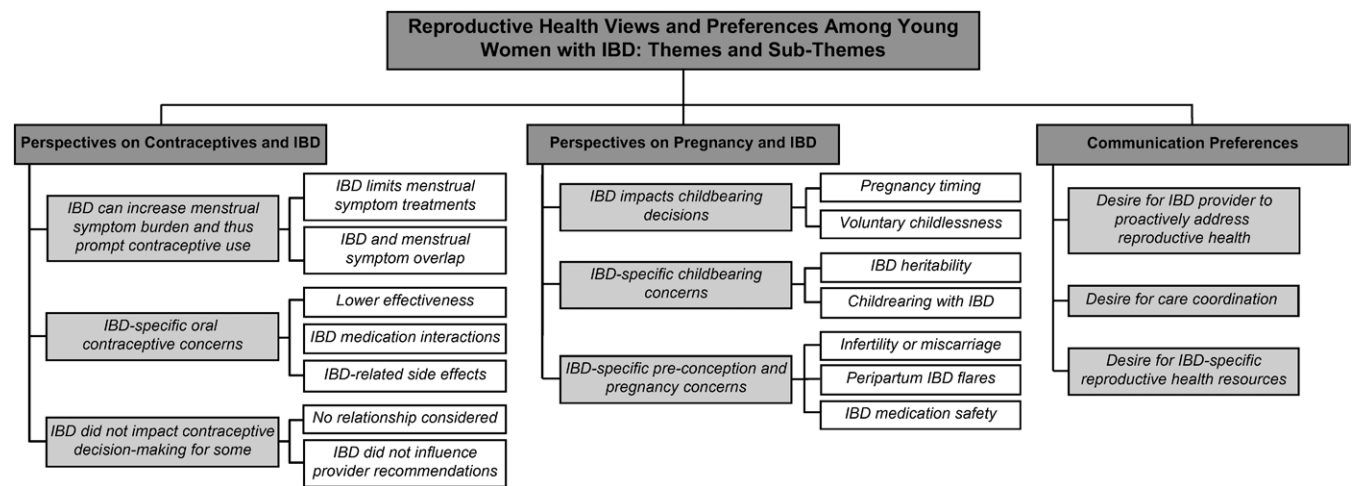


Figure 1. Study themes and sub-themes.

One participant shared that she specifically chose a hormonal IUD to mitigate her menstrual cycle because menstruation exacerbated her bloating, cramping, and diarrhea (26-year-old participant). Another woman started birth control specifically to control heavy periods and avoid worsening her Crohn’s disease-related anemia:

There was a solid four period, four-month stretch, where I was bleeding seven full days, absolutely overflowing everything. I couldn’t go a day without bleeding into my pants. I was like, ‘This is just too much. This feels like too much blood.’...Also...with Crohn’s disease, I’m anemic so I know that I shouldn’t be losing blood like that, anyway. (21-year-old participant)

One woman recalled that her IBD would become so symptomatic around her menstrual cycle that she discussed either starting oral contraceptives continuously to avoid having menses or changing her IBD treatment. Ultimately, she made the decision with her IBD provider to change her IBD treatment and her menstrual symptoms improved significantly (22-year-old participant).

Multiple participants reported that they started a contraceptive primarily to decrease menstrual pain and/or heavy bleeding.

Some participants sought contraceptive methods that would decrease menstrual pain and bleeding without worsening their gastrointestinal symptoms. One woman noted,

I wanted to find birth control methods that were easy on the system, like wouldn’t cause any upset stomach or anything. (28-year-old participant)

IBD-specific oral contraceptive concerns

A subset of participants expressed worry that their IBD might compromise the effectiveness of their oral birth control. One participant shared that she had become amenorrhoeic due to Crohn’s-related weight loss and was therefore afraid of unknowingly becoming pregnant. She was taking a birth control pill, but said,

I just don’t have clarity if it’s actually effective, so I still take it daily but then would prefer to double up on a contraceptive method just to ensure that I don’t get pregnant. (24-year-old participant)

Another participant had similar concerns:

I was warned by my doctors to make sure I was on two forms of birth control ... because oral medicine does not work as well when you are in an active flare. (26-year-old participant)

Others shared worries about contraceptives causing blood clots. One woman remarked,

I have concerns about the risks of birth control combined with the risks of being in an IBD flare. I know both of those can increase risks of blood clots. (22-year-old participant)

In reference to the combined oral contraceptive pill, another participant said,

In several studies I saw, it showed that it does increase blood-clotting risk after long-term use of estrogen pills. IBD patients are also [known] to have higher risk of blood clots, so I might as well reduce my risk somewhere'cause I can't exactly get rid of the IBD risk. (22-year-old participant)

She was one of a few participants who shared that they had personally read medical literature to learn about reproductive health and IBD.

Some women with IBD worried that oral birth control pills would interfere with their IBD medications. One said,

I think one of my general concerns that I always ask doctors about is whether any of my Crohn's medications, or whether the birth control, whether there's any interactions that will lessen each other's effectiveness? (22-year-old participant)

Other participants had questions about how contraceptives would alter IBD symptoms or future fertility. Some women desired a low-maintenance birth control because of their IBD:

I already take a lot of medicines for my Crohn's and other conditions that I deal with. One less thing to worry about, whether it's a monthly, every 90-day shot, or something that's implanted in me is much easier on me for my medical care. (30-year-old participant)

IBD did not impact contraceptive decision-making for some

On the other hand, several respondents reported that their IBD did not influence their contraception decisions. Some had started a contraceptive prior to their IBD diagnosis and continued it after their diagnosis without considering IBD as a potential reason to change their form of contraception. When asked whether IBD had influenced her decision-making about birth control, one woman replied,

Really not too much, because I was on a pill well before I got diagnosed with ulcerative colitis and well before my surgeries for J-pouch ... Things were going fine, and I didn't see IBD as a need to change anything. (28-year-old participant)

Some participants shared that they had not considered or worried about a relationship between contraception and IBD

because their healthcare providers had not made any contraceptive recommendations based on their IBD diagnosis. One woman recalled,

Anytime I've had a gyno, I've mentioned [my IBD], especially after college. I tell them that I have Crohn's, when I started birth control, things like that. They've never really had concerns about what type of birth control I'm on. (27-year-old participant)

When asked whether she had any IBD-related concerns about contraception, another participant replied,

I guess not, because I feel like if a doctor didn't bring it up to me, then I don't have a need to be concerned about it. (28-year-old participant)

Theme 2: Perspectives on pregnancy and IBD

IBD impacts childbearing decisions

Most participants desired pregnancy in the long- or short-term (63%) or felt undecided on whether they wanted to have a child in the future (17%). One participant said,

I've always wanted to be a mom ... I walk down the street, and I see a little kid, and I'm like—I can feel my ovaries singing. (30-year-old participant)

Among the subset who desired pregnancy, some reported that their disease would impact pregnancy timing. Several expressed a desire to achieve and maintain disease remission for a period before trying to become pregnant. One said,

Yes [I want to become pregnant in the future], but I know that, at least with my situation, I would have to be fully in remission to go through with a pregnancy and stuff like that, since the medication [interacts] with the fetus. (21-year-old participant)

One 28-year-old participant, who had been pregnant 3 times, started trying to conceive in her early 20s because she thought that having kids while younger would optimize her prenatal health.

Among those who desired or were undecided about pregnancy, most (84% and 80%, respectively) reported IBD-related pregnancy concerns. One participant said,

In the long term, I do think that I will want to be pregnant someday, but right now, it's something that makes me a little nervous. I feel like my body doesn't—it seems like it'd be sort of a hostile environment, maybe, to be pregnant, and it feels like something that would probably aggravate my symptoms. I deal a lot with nausea already, and it feels like something that pregnancy would make a lot worse. (26-year-old participant)

A substantial minority (20%) did not ever want to become pregnant, and, of this subgroup, 4 participants (67%) stated that having IBD influenced their decision. One participant explained that she does not plan to have children due to concerns about pregnancy complications and jeopardizing her disease remission. She reflected,

I have spent a lot of time in hospitals ... I'm aware of a lot of complications that could come from pregnancy. Especially once I had achieved remission for the first time, I was more solidified that I don't want to lose this to bring a life into the world when there's plenty of other things I could do. (30-year-old participant)

Another participant shared why she does not want to have children:

Part of it's because of IBD. ... I wouldn't want to carry a child, because I've had multiple surgeries, and I would be worried about how [pregnancy] would go and how medication might affect the baby. (25-year-old participant)

IBD-specific childbearing concerns

Many participants reported concerns about passing on IBD to future children. Some reflected on the personal difficulties they faced as children with IBD and how they did not want to put their children through a similar experience. One participant recalled,

I just remember how confusing and frustrating that was for me growing up, with not really being able to understand it fully. Being so young having it ... you don't really know what's happening. It's just like you're in pain, you're experiencing all these things that you can't really explain to other kids. (19-year-old participant)

One respondent even wondered about the ethical implications of having a child:

While I know I've always wanted to be a mom and stuff like that, part of me sits back and says, like, 'Is that selfish, because you know you have such a risk of potentially passing something on to your child?' (30-year-old participant)

Several participants had the misconception that passing IBD to future children was highly likely, and one respondent mistakenly thought that IBD could be diagnosed via prenatal genetic testing. One participant shared,

I think that was part of my reason for not being so on board with having kids, especially when I was younger, because I had so many just issues growing up because of Crohn's, and I knew the likelihood of me having a child with Crohn's is pretty high or much higher than someone without (27-year-old participant).

A subset of participants expressed hesitation about becoming parents while living with a chronic disease, particularly considering the health, financial, and logistical challenges they already faced due to IBD. One participant stated,

I don't think I'd be ready to have a kid and just experience that while also trying to deal with the disease. I just don't feel like I'm mature enough to handle all of that. (21-year-old participant).

Given the challenges of taking care of a child while living with IBD, multiple participants said that finding a supportive partner would be essential for them to feel comfortable having a baby. One woman shared that, while she might feel okay raising a child by herself if she did not have IBD, because of her ulcerative colitis she feels strongly about finding a partner before having a child:

I think with IBD, I would just be nervous about having my health in not a good state. I would definitely want to be in a very great relationship with a great partner that can support the whole process. (25-year-old participant)

IBD-specific pre-conception and pregnancy concerns

Many respondents shared concerns that having IBD would lead to infertility, miscarriage, and/or harm to a fetus. One participant explained,

The one thing that always stuck in my head is ... how has my health affected my fertility. I know I'll be at higher risk when ... if I have the opportunity to be pregnant. (30-year-old participant)

One participant even noted that her future fertility motivates her to control her disease:

I do think that a big reason that I try to control my disease is first for my health but then second for the ability to get pregnant someday. (24-year-old participant)

Some women noted that fertility concerns influenced their decision-making about surgical management of their disease. One participant recalled discussing colorectal surgery with her gynecologist:

Also thinking about the possibility of surgery for my ulcerative colitis and how that affects potentially fertility, especially if it's a planned colectomy—do I try and wait until after I have children or not? (22-year-old participant)

One participant reported a prior misconception that having IBD ensured infertility:

...I genuinely thought, since I had IBD, I couldn't get pregnant. (24-year-old participant)

Another participant said,

Right now, I'm doing pretty well, but if I get sick with my Crohn's, I could end up having to be in the hospital. I don't know if the baby would be okay throughout all that, or if I would miscarry or something. (19-year-old participant)

Concern about the possibility of an IBD flare during pregnancy came up repeatedly during interviews. One participant shared,

Right now ... I'm in remission. I feel very good ... What if getting pregnant messes up everything and just I start feeling as sick as I felt when I first got diagnosed. (21-year-old participant)

Other participants shared questions they had about pregnancy in IBD. One woman asked,

Would I have to change what medicine I'm on for the UC? Would it exacerbate symptoms? I tend to have alternating constipation and diarrhea. I'm not regular, and pregnancy tends to mess with that too. Would I have to change the regimens that have kept me stable for the past five, eight years? (26-year-old participant)

For another participant, such fears led her to favor adoption over pregnancy:

I think that for me, for the longest time, I really just viewed pregnancy as you're just gonna be sick for nine months. I was like, well, I'm already sick as it is. Why? When there are so many other children who are just wanting to be loved, so why not do it that way? (24-year-old participant)

One participant had the misconception that having Crohn's disease guaranteed a complicated pregnancy:

I'd always heard growing up ... if you had Crohn's and you became pregnant, you would flare really terrible. (27-year-old participant)

Multiple participants expressed concerns about peripartum IBD medication safety, many of which reflected misconceptions. For example, several young women with IBD erroneously thought that they would have to discontinue biologic medications and/or immunomodulator medications when pregnant or trying to conceive. One participant on biologic therapy expressed multiple IBD-related pregnancy fears:

Yeah, I just think, one, knowing that I take a really strong medication, I don't know—I'd have to take that while being pregnant—what that could do to a pregnancy ... it's still scary to think that, hey, I'm putting this really strong immunosuppressant while I'm trying to conceive and carry a child. (21-year-old participant)

A respondent on azathioprine, a medication shown to be safe in pregnancy, had the following misconception:

Just being on [azathioprine] causes greater risk for the child, and that is not something that I would want to put my child [through]. (21-year-old participant)

Theme 3: Communication Preferences

Desire for IBD provider to proactively address reproductive health

Many participants indicated that GI providers should broach the subject of reproductive health and IBD in a confidential setting and take the patient's lead on the discussion. One woman said,

I think I would like pediatric GI doctors to be ... more equipped or receptive to talking about reproductive health. The fact that I had a conversation with mine about it was great, but it was pretty minimal. (22-year-old participant)

This respondent felt disappointed that her doctor never told her that IBD can worsen menstrual symptoms.

Participants noted that discussing reproductive health could feel uncomfortable. One participant said,

For me growing up, my mom was always there for my pediatric GI appointments ... you don't want to talk about contraception in front of your mom or being around the GI pediatrician you've known since you were eight years old. It's just awkward. (27-year-old participant)

As such, some women suggested that providers bring up the subject of reproductive health themselves and do so in a one-on-one setting. A participant shared,

...I believe that maybe the gastroenterologist should say, 'Do you have any concerns about reproductive health in relationship to GI?', kind of prompt it, because honestly it wasn't ever something that I thought I could or should ask my GI doctor. (19-year-old participant)

Several respondents preferred to hear information about reproductive health early in life, before becoming sexually active. One respondent expressed why she feels strongly about starting these discussions early:

I could just decide one day that I want to become pregnant and have never had these conversations and be on medication that I shouldn't be on. They're definitely important conversations to have, I think, even before a patient brings it up. (25-year-old participant)

Several participants believed that providers should take the opportunity to discuss pregnancy-related safety when starting a new medication, such as one participant who felt fortunate that her GI provider told her that adalimumab was safe in pregnancy:

Being told what's safe, what's not safe [in pregnancy] at the time you're prescribed [a new medication] I think is really nice too. (27-year-old participant)

However, participants also wanted providers to take cues from their patients and delve into the subject only as deeply as the patient desired. One woman said,

I... think that we can't assume that everyone wants to talk about family planning, but it's good to probe and then see. (24-year-old participant)

Desire for care coordination

Perspectives varied on whether IBD-specific reproductive health counseling should come primarily from the IBD provider, gynecologist, or primary care provider. Most participants preferred a provider with whom they trusted, felt the most comfortable, and perceived as knowledgeable on the topic. However, many participants felt that this type of counseling should ideally occur as a coordinated effort between specialties. Many participants wished that their gastroenterology and obstetrics/gynecology providers shared a physical location, were part of the same system, or at least had open lines of communication. One woman said,

If it were a collaboration, in the same one room, and talk to my GI specialist and the OB/GYN, at the same time, that would be perfect. (28-year-old participant)

One participant, who recalled looping in her gastroenterologist after discussing birth control with her gynecologist, explained her rationale:

My GI is my main care. Any medicine we considered, whether it's psychiatric, whether it's reproductive, asthma, my GI is the first stop to make sure that she doesn't know of any issues. (30-year-old participant)

Some participants felt that multidisciplinary collaboration would be particularly important prior to trying to conceive:

When I come to a point in my life that I want to become pregnant, I would seek out more of an integrated team. I would like my GI totally to be in communication with my OB/GYN or just have some type of specific knowledge. (25-year-old participant)

Desire for IBD-specific reproductive health resources

Some participants expressed a desire for IBD-specific reproductive health informational materials or articles that they could review and then ask their providers any questions that arose. One woman said,

I think it would be wonderful and important to have a standalone thing about fertility and birth control specifically just so that for patients who ask about it, you offer that. (24-year-old participant)

Other participants wished to be connected to other young women with IBD willing to share their real-life reproductive health resources, such as through a support group. One participant stated,

I think that if [contraception is] gonna be approached as an IBD issue, then there should be some evidence or some examples of people who have been on birth control and also have IBD or Crohn's. (19-year-old participant)

Discussion

This study investigated the perspectives of young women with IBD regarding reproductive health and IBD-specific reproductive health counseling. Most participants had IBD-specific questions and concerns about contraception and pregnancy. Many found menstrual symptoms especially burdensome due to their IBD, and these symptoms often led them to start a contraceptive. Several participants expressed dissatisfaction with the amount of IBD-specific reproductive health counseling they had received. Participants suggested that IBD providers can improve reproductive health counseling by bringing up the topic of reproductive health and how it relates to IBD early in adolescence in a confidential, one-on-one setting, and by taking the patient's lead on the discussion. They also recommended that IBD providers offer IBD-specific reproductive health resources, including evidence-based handouts

and opportunities for women with IBD to hear real-life reproductive experiences from peers with IBD. Many participants wished that their gastroenterology provider would coordinate care with their primary reproductive health provider, including the primary care physician and/or gynecologist. See [Table 2](#) for a list of suggestions that providers can use to improve reproductive health counseling for young women with IBD, based on participant's communication preferences and their direct suggestions.

This study lends support to a small but growing body of literature documenting IBD-related reproductive health concerns among women with IBD. Consistent with our study findings, previous research suggests that women with IBD experience high symptom burden during menses, whether from increased IBD activity, hormonally mediated menstrual symptoms, or a combination of the 2.^{44,45} Some participants reasonably planned to wait to attempt conception once they had achieved stable remission, as research suggests better pregnancy and neonatal outcomes among pregnant people who achieve and maintain IBD remission throughout pre-conception and pregnancy.^{2,46,47} Similarly, a few participants had appropriate concerns about IBD-related surgery and/or active disease leading to infertility or miscarriage, as studies indicate that multifactorial mechanisms such as pelvic inflammation of the reproductive organs and surgical adhesions can impair fertility and increase miscarriage risk.⁴⁸

While many participants had evidence-based concerns about the relationship between reproductive health and IBD, we also observed misconceptions and a lack of IBD-specific reproductive health knowledge. A minority of women did not factor their chronic disease into decisions about reproductive health at all, largely because they either did not recognize that IBD influences reproductive health or because they did not think that their providers considered IBD when counseling on reproductive health. Several participants thought that passing IBD on to their children was highly likely, even though the risk of that a child will develop IBD if one parent has IBD is approximately 1 in 10.⁴⁹ Contrary to views expressed by several participants, most biologic and immunomodulator medications are safe in pregnancy,² and the AGA recommends continued use of these medications during the peripartum period, with the exception of methotrexate.⁹ Moreover, some respondents with fertility concerns lacked the nuanced understanding that those with well-controlled IBD and no history of pelvic surgery have similar infertility rates to the general population.⁴⁸ A few participants thought that having an IBD flare in pregnancy was virtually guaranteed, even though pregnant people with Crohn's disease have similar outcomes to those who are not pregnant and, while pregnancy is associated with relapse in ulcerative colitis, over half of pregnant people with ulcerative colitis remain in remission throughout pregnancy.⁴⁷ Lack of reproductive health knowledge and misconceptions among women with IBD have been similarly reported in previous work.^{7,50} Misconceptions about the relationship between IBD and pregnancy, and concerns of having a disease recurrence due to pregnancy, are associated with higher rates of voluntary childlessness in IBD.^{6,51} Conversely, pregnancy-specific IBD knowledge and being seen at a dedicated IBD-pregnancy clinic are negative predictors of voluntary childlessness.⁵¹ Accordingly, European, Canadian, and United States guidelines recommend pregnancy and family planning education for all patients with IBD of childbearing age.^{8,9,52}

Table 2. Suggestions for inflammatory bowel disease (IBD) providers to improve reproductive health counseling for their young female patients with IBD.^a

1. Bring up the topic of reproductive health and how it relates to IBD when patients are early in adolescence, and in a confidential, one-on-one setting.
 - a. When starting a new IBD medication, advise the patient if this medication could have implications or considerations for future pregnancy.
2. Take cues from the patient to individualize the extent and focus of reproductive health counseling, and invite future discussions.
3. Listen closely to the patient's reproductive health preferences and wishes.
4. Ask the patient with whom they would prefer to discuss reproductive health, and provide referrals or recommendations to other providers if applicable.
 - a. Inquire about whether patients have a gender preference for reproductive health counseling, and if so, accommodate to the extent possible with referrals to colleagues or other specialists of their preferred gender.
5. Offer to reach out to the patient's reproductive health provider, such as their OB/GYN and/or primary care provider, to coordinate reproductive health care and provide IBD-specific guidance.
6. Provide IBD-specific reproductive health resources to your patients, such as the following online resources:
 - a. Crohn's and Colitis Foundation
 - b. We Care, an organization supporting IBD and motherhood
 - c. MotherToBaby™ organization, Pregnancy and Breastfeeding Exposures for Inflammatory Bowel Disease subsection
 - d. The PIANO study
7. Provide opportunities for your patients to hear real-life accounts of reproductive health experiences from other women with IBD, with resources such as:
 - a. IBDMoms organization
 - b. Girls with Guts organization
 - c. Generation Patient organization

^aBased upon study participant's direct suggestions and their communication preferences.

Other IBD-related reproductive health concerns raised by participants highlighted important gaps in evidence. While estrogen-based contraceptives and active IBD independently increase the risk for blood clots,^{53,54} the absolute risk of venous thromboembolism from estrogen-based contraceptive use in IBD remains unclear, particularly among young women. Accordingly, the 2023 European Crohn's and Colitis Guidelines recommend a careful assessment of thrombotic risk before prescribing an estrogen-based contraceptive to someone with IBD, although they note that estrogen-based contraceptives are generally low-risk in people with IBD.⁸ The CDC Medical Eligibility Criteria for Contraceptive Use includes similar recommendations, and they specify that for those with VTE risk factors including active or extensive disease, surgery, corticosteroid use, immobilization, vitamin deficiencies, or fluid depletion, the risks of estrogen-based contraceptives generally outweigh the benefits.³⁴ Moreover, although it is mechanistically plausible that oral contraceptive pills may work less effectively in the setting of active Crohn's disease, given that active small bowel disease could impair medication absorption,⁹ further studies are needed to determine whether active Crohn's disease truly decreases the efficacy of oral birth control.

In general, participants wanted to learn more about the link between reproductive health and IBD. Several respondents expressed dissatisfaction with the amount of IBD-specific information and counseling they received. However, a subset of participants felt uncomfortable bringing up the topic of reproductive health with their providers. These findings parallel sentiments expressed by young women with other chronic diseases.^{17,24,25} In contrast, however, a qualitative study of women ages 18-43 with pediatric-onset IBD receiving care at an academic medical center found that most respondents felt satisfied with the "timing, content, and comfort" of past reproductive health conversations with their IBD providers.⁵⁰ This discrepancy may be partially explained by center-specific

differences in gastroenterology providers' comfort in discussing reproductive health. The present study included women from 13 states; the participants who expressed a desire for more resources and better counseling from their IBD providers received care from a variety of public and private institutions across the United States. Thus, our findings may be more transferable to the US population. Indeed, survey-based and retrospective studies of US women with IBD suggest that most IBD physicians provide minimal reproductive health counseling.^{7,26}

Another major reason for this difference may be that the prior study elicited reproductive experiences across the reproductive age spectrum, while we asked participants to focus on their experiences in their teens and early 20s. Compared to younger menstruating people with IBD, those in their mid-to late-20s and beyond have had more time to see a reproductive health provider, experience pregnancy, and/or have their reproductive health questions answered. Therefore, they may feel more satisfied with their reproductive health understanding and counseling experiences than younger people. A cross-sectional survey of women with IBD substantiates this possibility, as only 18% of those aged 18-25 were satisfied with their physician's counseling on family planning and pregnancy in IBD, versus 28% of those aged 26-30 and 33% of those aged 31-35 ($P < .01$).⁷ Moreover, the survey found that providers rarely discussed family planning and pregnancy issues with childless or single women with IBD.⁷

Strengths of this study include its qualitative approach, which allowed us to explore patient perspectives in-depth. We recruited a diverse sample with respect to geography and sexual orientation, with representation from 13 US states and 7 self-identified sexual orientation categories. Moreover, our sample parallels the racial and ethnic distribution of the US IBD population: 79% of the US IBD population identifies as White race and 13% identify as Hispanic ethnicity.⁴¹ Our sample size also meets the latest publication standard for

qualitative research.⁵⁵ However, because we only included *cis*-women in this study, our findings may not apply to other pregnancy-capable people with IBD. Moreover, the study did not capture perspectives from people with IBD who did not ever consider using or use contraception. The characteristics of the interviewees, including gender, race, ethnicity, and occupation, might also have influenced interview interactions and impacted our findings. E.B. did not interview any patients from North Carolina to avoid the potential for bias or discomfort given her occupation as a pediatric gastroenterologist. While IBD diagnosis was confirmed by a provider for participants recruited from the IBD clinics, we relied on participant self-report of IBD diagnosis for those recruited through online networks. However, IBD self-report was found to be highly reliable in IBD Partners validation work, with 95% of respondents correctly reporting their diagnosis.⁵⁶

Conclusion

In summary, participants in our study had concerns about how IBD impacts reproductive health and desired better disease-specific reproductive health counseling. Resources on contraception, pregnancy, and menstrual symptoms tailored for young women with IBD may better prepare them to make informed decisions and potentially prevent negative outcomes ranging from menstrual-related school/work absences to unintended pregnancy and contraceptive-related adverse events. While awaiting age-specific resources, IBD providers can improve reproductive health for young women with IBD by integrating IBD-specific reproductive health counseling into routine care early in adolescence in a confidential, one-on-one setting. We recommend that IBD providers take their patient's lead on the discussion, coordinate care with reproductive health providers, and help their patients to interpret existing reproductive health resources in the context of their disease.

Supplementary Material

Supplementary data are available at *Crohn's & Colitis* 360 online.

Acknowledgments

Thank you to the members of the Patient Advisory Board for your contributions to this work and to all the patient participants. Thank you to the IBD Partners and ImproveCareNow networks for facilitating recruitment. Thank you to Ally Giunta MS, Rachel Cooke MS, Riley Craig BS, David Seligson BA, Margie Boccieri BA, and the UNC Pediatric Gastroenterology Division for assisting with study recruitment and execution. Erica Brenner has obtained a license from Adobe Stock™ to use the artwork included in the graphical abstract.

Author Contributions

E.J.B.: study design, data collection, data analysis, patient recruitment, and manuscript writing; M.E.G.: Data collection, data analysis, and manuscript editing; C.B.T.: Data collection, data analysis, and manuscript editing; A.G.B.: Data interpretation and manuscript editing; M.C.D.: Study design

and manuscript editing; X.Z.: Data cleaning and analysis and manuscript editing; M.D.L.: Study design and manuscript editing; M.D.K.: Study design, data interpretation, and manuscript editing; M.B.: Study design, supervision of data collection and analysis, data interpretation, and manuscript editing. All authors provided final approval of the submitted manuscript.

Funding

This work was supported by grants from the National Institutes of Health [P30 DK034987 to E.J.B.] and the University of North Carolina School of Medicine Physician Scientist Training Program Faculty Award [to E.J.B.]. The project was also supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health [UM1TR004406]. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Conflicts of Interest

These authors disclose the following: Millie D. Long has served as a consultant for AbbVie, UCB, Takeda, Janssen, Pfizer, Salix, Valeant, and Target Pharmsolutions, and has received research support from Pfizer and Takeda. Marla C. Dubinsky has served as a consult for AbbVie, Arena Pharmaceuticals, Boehringer Ingelheim, Bristol-Meyers Squibb, Celgene, Eli Lilly, F. Hoffmann-LaRoche, Genentech, Gilead, Janssen, Pfizer, Prometheus Biosciences, Takeda, and UCB SA; has contracted research with AbbVie, Janssen, Pfizer, and Prometheus Biosciences; has an ownership interest in Trelus Health; and has received licensing fees from Takeda. Michael D. Kappelman has served as a consultant for Takeda and Eli Lilly and has received research support from AbbVie and Janssen. The remaining authors disclose no conflicts.

Data Availability

The data underlying this article will be shared on reasonable request to the corresponding author.

References

1. Gawron LM, Sanders J, Steele KP, Flynn AD. Reproductive planning and contraception for women with inflammatory bowel diseases. *Inflamm Bowel Dis*. 2016;22(2):459-464. doi:10.1097/MIB.0000000000000606
2. Mahadevan U, Long MD, Kane SV, et al.; Crohn's Colitis Foundation Clinical Research Alliance. Pregnancy and neonatal outcomes after fetal exposure to biologics and thiopurines among women with inflammatory bowel disease. *Gastroenterology*. 2021;160(4):1131-1139. doi:10.1053/j.gastro.2020.11.038
3. Limdi JK, Farraye J, Cannon R, Woodhams E, Farraye FA. Contraception, venous thromboembolism, and inflammatory bowel disease: what clinicians (and patients) should know. *Inflamm Bowel Dis*. 2019;25(10):1603-1612. doi:10.1093/ibd/izz025
4. Nee J, Feuerstein JD. Optimizing the care and health of women with inflammatory bowel disease. *Gastroenterol Res Pract*. 2015;2015:435820. doi:10.1155/2015/435820
5. Gawron LM, Gawron AJ, Kasper A, Hammond C, Keefer L. Contraceptive method selection by women with inflammatory bowel diseases: a cross-sectional survey. *Contraception*. 2014;89(5):419-425. doi:10.1016/j.contraception.2013.12.016

6. Marri SR, Ahn C, Buchman AL. Voluntary childlessness is increased in women with inflammatory bowel disease. *Inflamm Bowel Dis*. 2007;13(5):591-599. doi:10.1002/ibd.20082
7. Walldorf J, Brunne S, Gittinger FS, Michl P. Family planning in inflammatory bowel disease: childlessness and disease-related concerns among female patients. *Eur J Gastroenterol Hepatol*. 2018;30(3):310-315. doi:10.1097/MEG.0000000000001037
8. Torres J, Chaparro M, Julsgaard M, et al. European Crohn's and Colitis guidelines on sexuality, fertility, pregnancy, and lactation. *J Crohns Colitis*. 2023;17(1):1-27. doi:10.1093/ecco-jc/jjac115
9. Mahadevan U, Robinson C, Bernasko N, et al. Inflammatory bowel disease in pregnancy clinical care pathway: a report from the American Gastroenterological Association IBD Parenthood Project Working Group. *Gastroenterology*. 2019;156(5):1508-1524. doi:10.1053/j.gastro.2018.12.022
10. Counseling adolescents about contraception. Committee Opinion No. 710. American College of Obstetricians and Gynecologists. *Obstet Gynecol*. 2017;130(2):e74-e80. doi:10.1097/AOG.0000000000002234
11. Roberts ST, Kennedy BL. Why are young college women not using condoms? Their perceived risk, drug use, and developmental vulnerability may provide important clues to sexual risk. *Arch Psychiatr Nurs*. 2006;20(1):32-40. doi:10.1016/j.apnu.2005.08.008
12. Paat YF, Margaret Markham C. Young women's sexual involvement in emerging adulthood. *Soc Work Health Care*. 2016;55(8):559-579. doi:10.1080/00981389.2016.1199454
13. Murray Horwitz ME, Pace LE, Ross-Degnan D. Trends and disparities in sexual and reproductive health behaviors and service use among young adult women (aged 18-25 years) in the United States, 2002-2015. *Am J Public Health*. 2018;108(4):S336-S343. doi:10.2105/AJPH.2018.304556
14. Kaye K, Suellentrop K, Sloup C. *The Fog Zone: How Misperceptions, Magical Thinking, and Ambivalence put Young Adults at Risk for Unplanned Pregnancy*. The National Campaign to Prevent Teen and Unplanned Pregnancy; 2009. Accessed October 12, 2021. <https://powertodecide.org/sites/default/files/resources/primary-download/fog-zone-full.pdf>
15. Suris JC, Parera N. Sex, drugs and chronic illness: health behaviours among chronically ill youth. *Eur J Public Health*. 2005;15(5):484-488. doi:10.1093/eurpub/cki001
16. Todd N, Black A. Contraception for adolescents. *J Clin Res Pediatr Endocrinol*. 2020;12(Suppl 1):28-40. doi:10.4274/jcrpe.galenos.2019.2019.S0003
17. Carandang K, Mruk V, Ardoin SP, et al. Reproductive health needs of adolescent and young adult women with pediatric rheumatic diseases. *Pediatr Rheumatol Online J*. 2020;18(1):66. doi:10.1186/s12969-020-00460-7
18. Kazmerski TM, Borrero S, Sawicki GS, et al. Provider attitudes and practices toward sexual and reproductive health care for young women with cystic fibrosis. *J Pediatr Adolesc Gynecol*. 2017;30(5):546-552. doi:10.1016/j.jpog.2017.01.009
19. Kazmerski TM, Gmelin T, Slocum B, Borrero S, Miller E. Attitudes and decision making related to pregnancy among young women with cystic fibrosis. *Matern Child Health J*. 2017;21(4):818-824. doi:10.1007/s10995-016-2181-z
20. Kazmerski TM, Nelson EB, Newman LR, et al. Interprofessional provider educational needs and preferences regarding the provision of sexual and reproductive health care in cystic fibrosis. *J Cyst Fibros*. 2019;18(5):671-676. doi:10.1016/j.jcf.2019.01.015
21. Kazmerski TM, Sawicki GS, Miller E, et al. Sexual and reproductive health care utilization and preferences reported by young women with cystic fibrosis. *J Cyst Fibros*. 2018;17(1):64-70. doi:10.1016/j.jcf.2017.08.009
22. Scott N, Maslyanskaya S. Contraceptive needs of adolescents with chronic illness. *Pediatr Ann*. 2019;48(2):e78-e85. doi:10.3928/19382359-20190121-01
23. Cystic Fibrosis: All Guides. The Center for Young Women's Health, Boston Children's Hospital. Updated January 2020. Accessed October 13, 2021. <https://youngwomenshealth.org/cystic-fibrosis-all-guides/>
24. Kazmerski TM, Borrero S, Tuchman LK, et al. Provider and patient attitudes regarding sexual health in young women with cystic fibrosis. *Pediatrics*. 2016;137(6):e20154452. doi:10.1542/peds.2015-4452
25. Nixon GM, Glazner JA, Martin JM, Sawyer SM. Female sexual health care in cystic fibrosis. *Arch Dis Child*. 2003;88(3):265-266. doi:10.1136/adc.88.3.265
26. Gawron LM, Hammond C, Keefer L. Documentation of reproductive health counseling and contraception in women with inflammatory bowel diseases. *Patient Educ Couns*. 2014;94(1):134-137. doi:10.1016/j.pec.2013.09.013
27. Burke A, Donnelly M. Reproductive health in transitional care: do ask, do tell. *SIGM Forum*. 2013;36(4):1.
28. NASPGHAN North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. Inflammatory Bowel Disease Monographs. Healthcare Provider Checklist for Transitioning a Patient from Pediatric to Adult Care. Accessed October 22, 2021. http://www.naspgan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProvider_TransitionfromPedtoAdult.pdf
29. Breglio KJ, Rosh JR. Health maintenance and vaccination strategies in pediatric inflammatory bowel disease. *Inflamm Bowel Dis*. 2013;19(8):1740-1744. doi:10.1097/MIB.0b013e318281f5b5
30. DeFilippis EM, Sockolow R, Barfield E. Health care maintenance for the pediatric patient with inflammatory bowel disease. *Pediatrics*. 2016;138(3):e20151971. doi:10.1542/peds.2015-1971
31. Turner D, Ruemmele FM, Orlanski-Meyer E, et al. Management of paediatric ulcerative colitis, part 1: ambulatory care-an evidence-based guideline from European Crohn's and Colitis Organization and European Society of Paediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*. 2018;67(2):257-291. doi:10.1097/MPG.0000000000002035
32. van der Woude CJ, Ardizzone S, Bengtson MB, et al.; European Crohn's and Colitis Organization. The second European evidenced-based consensus on reproduction and pregnancy in inflammatory bowel disease. *J Crohns Colitis*. 2015;9(2):107-124. doi:10.1093/ecco-jc/jju006
33. Brenner EJ, Zhang X, Long MD, Dubinsky MC, Kappelman MD. High use of estrogen-based contraceptives in young women with inflammatory bowel disease in the United States. *Clin Gastroenterol Hepatol*. 2023;22(2):427-429.e28. doi:10.1016/j.cgh.2023.07.007
34. Nguyen AT, Curtis KM, Tepper NK, et al. U.S. medical eligibility criteria for contraceptive use, 2024. *MMWR Recomm Rep*. 2024;73(4):1-126. doi:10.15585/mmwr.rr7304a1
35. Doyle L, McCabe C, Keogh B, Brady A, McCann M. An overview of the qualitative descriptive design within nursing research. *J Res Nurs*. 2020;25(5):443-455. doi:10.1177/1744987119880234
36. Inclusive Science Program: North Carolina Translational and Clinical Sciences Institute. National Center for Advancing Translational Sciences (NCATS), National Institutes of Health. Updated 2024. Accessed October 30, 2024. <https://tracs.unc.edu/index.php/services/inclusive-science-program>
37. Ellis JA, Malalasekera VS, Allan C, et al. Systems-level change to alleviate barriers to cancer clinical trial access for adolescents and young adults in Australia. *J Adolesc Young Adult Oncol*. 2022;11(2):173-180. doi:10.1089/jayao.2021.0026
38. Feldman ECH, Durkin LK, Bugno L, et al. Communication about medication by providers-adolescent and young adult version: confirmatory factor analyses. *J Pediatr Psychol*. 2021;46(5):599-608. doi:10.1093/jpepsy/jsab009
39. Long MD, Kappelman MD, Martin CF, et al. Development of an internet-based cohort of patients with inflammatory bowel diseases (CCFA Partners): methodology and initial results. *Inflamm Bowel Dis*. 2012;18(11):2099-2106. doi:10.1002/ibd.22895
40. Crandall W, Kappelman MD, Colletti RB, et al. ImproveCareNow: the development of a pediatric inflammatory bowel disease

- improvement network. *Inflamm Bowel Dis*. 2011;17(1):450-457. doi:10.1002/ibd.21394
41. Barnes EL, Nowell WB, Venkatachalam S, Dobes A, Kappelman MD. Racial and ethnic distribution of inflammatory bowel disease in the United States. *Inflamm Bowel Dis*. 2022;28(7):983-987. doi:10.1093/ibd/izab219
 42. Crohn's & Colitis Foundation. Accessed December 30, 2024. <https://www.crohnscolitisfoundation.org/>
 43. Pregnancy In IBD and Neonatal Outcomes. Accessed December 30, 2024. <https://pianostudy.org/>
 44. Lim SM, Nam CM, Kim YN, et al. The effect of the menstrual cycle on inflammatory bowel disease: a prospective study. *Gut Liver*. 2013;7(1):51-57. doi:10.5009/gnl.2013.7.1.51
 45. Bharadwaj S, Barber MD, Graff LA, Shen B. Symptomatology of irritable bowel syndrome and inflammatory bowel disease during the menstrual cycle. *Gastroenterol Rep (Oxf)*. 2015;3(3):185-193. doi:10.1093/gastro/gov010
 46. Mahadevan U, Sandborn WJ, Li DK, Hakimian S, Kane S, Corley DA. Pregnancy outcomes in women with inflammatory bowel disease: a large community-based study From Northern California. *Gastroenterology*. 2007;133(4):1106-1112. doi:10.1053/j.gastro.2007.07.019
 47. Pedersen N, Bortoli A, Duricova D, et al.; European Crohn-Colitis Organisation-ECCO-Study Group of Epidemiology Committee-EpiCom. The course of inflammatory bowel disease during pregnancy and postpartum: a prospective European ECCO-EpiCom Study of 209 pregnant women. *Aliment Pharmacol Ther*. 2013;38(5):501-512. doi:10.1111/apt.12412
 48. Ali MF, He H, Friedel D. Inflammatory bowel disease and pregnancy: fertility, complications and treatment. *Ann Gastroenterol*. 2020;33(6):579-590. doi:10.20524/aog.2020.0536
 49. Noble CL, Arnott ID. What is the risk that a child will develop inflammatory bowel disease if 1 or both parents have IBD? *Inflamm Bowel Dis*. 2008;14(Suppl 2):S22-S23. doi:10.1002/ibd.20575
 50. Picciarelli Z, Stransky OM, Leech MM, et al. Exploring reproductive health decision experiences and preferences of women with pediatric-onset inflammatory bowel diseases. *Crohns Colitis* 360. 2022;4(1):otab083. doi:10.1093/crocol/otab083
 51. Laube R, Yau Y, Selinger CP, et al. Knowledge and attitudes towards pregnancy in females with inflammatory bowel disease: an International, Multi-centre Study. *J Crohns Colitis*. 2020;14(9):1248-1255. doi:10.1093/ecco-jcc/jjaa047
 52. Nguyen GC, Seow CH, Maxwell C, et al.; IBD in Pregnancy Consensus Group. The Toronto Consensus Statements for the management of inflammatory bowel disease in pregnancy. *Gastroenterology*. 2016;150(3):734-757.e1. doi:10.1053/j.gastro.2015.12.003
 53. Peragallo Urrutia R, Coeytaux RR, McBroom AJ, et al. Risk of acute thromboembolic events with oral contraceptive use: a systematic review and meta-analysis. *Obstet Gynecol*. 2013;122(2 pt 1):380-389. doi:10.1097/AOG.0b013e3182994c43
 54. Kappelman MD, Horvath-Puho E, Sandler RS, et al. Thromboembolic risk among Danish children and adults with inflammatory bowel diseases: a population-based nationwide study. *Gut*. 2011;60(7):937-943. doi:10.1136/gut.2010.228585
 55. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol*. 2018;18(1):148. doi:10.1186/s12874-018-0594-7
 56. Irwin DE, Stucky BD, Thissen D, et al. Sampling plan and patient characteristics of the PROMIS pediatrics large-scale survey. *Qual Life Res*. 2010;19(4):585-594. doi:10.1007/s11136-010-9618-4