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RUNNING HEAD: TRANSITION TO MOTHERHOOD WITH IBD

When Your Pregnancy Echoes Your Illness:

Transition to Motherhood with Inflammatory Bowel Disease

Jihane Ghorayeb, School of Psychology, University of Leeds, UK

J.Ghorayeb12@leeds.ac.uk

Peter Branney, Division of Psychology, University of Bradford, Leeds, UK

p.branney@bradford.ac.uk

Christian P. Selinger, Department of Gastroenterology, Leeds Teaching Hospitals NHS Trust, Leeds UK christian.selinger@nhs.net

*Anna Madill, School of Psychology, Lifton Terrace, University of Leeds, Leeds, LS2 9JT, UK

A.l.madill@leeds.ac.uk T: +(44)1133435750 F: +(44)1133435749

*Corresponding author

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Abstract

Our aim is to provide an understanding of the experience of women with IBD who have made the transition to motherhood. Twenty-two mothers with IBD were recruited from around the UK. Semi-structured interviews were conducted and analyzed using thematic analysis. The central concept – *Blurred Lines* – offers a novel frame for understanding the transition to motherhood with IBD through identifying parallels between having IBD and becoming, and being, a mother. Parallels clustered into three main themes: *Need for Readiness*, *Lifestyle Changes*, and *Monitoring Personal and Physical Development*. Hence, women with IBD are in some ways well prepared for the challenges of motherhood even though, as a group, they tend to restrict their reproductive choices. We recommend health professionals initiate conversations about reproduction early and provide a multidisciplinary approach to pregnancy and IBD in which women have confidence that their on-going treatment will be integrated successfully with their maternity care.

When Your Pregnancy Echoes Your Illness:

Transition to Motherhood with Inflammatory Bowel Disease

Inflammatory bowel disease(IBD) is an umbrella term principally referring to two inflammation disorders affecting the digestive system: Ulcerative Colitis (UC) and Crohn's Disease (CD) (NHS, 2015). IBD is considered a chronic illness, punctuated by phases termed "flares" where the symptoms are active. Typically, individuals with UC or CD describe stomach pains, fatigue, fever, rectal bleeding, recurring diarrhea (often bloody with mucus or pus), and weight loss as common manifestations of their illness. Unfortunately, there is no cure for IBD but medication and surgical alternatives can ease the chronicity of the illness and more recently greater consideration and acceptance has brought to light the potential usefulness of fecal transplant; however, the media discourse and individuals remain hesitant (Chuong, O'Doherty, & Secko, 2015). In the US 1.3 million individuals live with IBD, with a slightly higher UC ratio in men and higher CD ratio in women; and in the UK 1 person in every 250 is diagnosed with IBD, 146,000 individuals have UC and 115,000 have CD with a slightly higher female-to-male ratio (ONS, 2016). IBD is more common in developed countries, but its incidence in developing countries is rapidly increasing. While the majority of patients experience adult onset in the third and fourth decade of life, many with IBD are diagnosed during adolescence and early adult life. As such, many women of child bearing age are affected by IBD.

Active CD can reduce a woman's fertility and IBD can increase the risk of complications during pregnancy and birth. However, even if a woman has IBD, 1/3 will get no worse and 1/3 will experience improvement in their symptoms during pregnancy (Beaulieu & Kane, 2011). Even so, women with IBD are more likely than healthy controls to be voluntarily childless (Marri, Ahn, & Buchman, 2006) and tend to have smaller families than the general population (Kwan & Mahadevan, 2010). The evidence suggests

these are not always informed choices given that "(t)here is a significant patient knowledge deficit about pregnancy and IBD resulting in unwarranted fears and anxiety" (Toomey & Waldron, 2013, p. 64). Half of women with IBD have poor knowledge of IBD-related pregnancy issues, and poor knowledge is associated with voluntary childlessness (Carbery, Ghorayeb, Madill, & Selinger, 2016; Selinger, Ghorayeb, & Madill, 2016).

The aim of this article is to provide an understanding of the experience of women with IBD who have made the transition to motherhood to increase the information available about planning and starting a family, and coping with young children, in the context of maternal IBD. Hence, a systematic search was conducted for research relevant to addressing the question: What is the experience of motherhood with IBD? Following Petticrew and Roberts (2006), a list of 72 key terms was created divided into four clusters. The first two covered IBD (e.g., *Crohn's Disease**) and mothers (e.g., *Matern**) and the latter two tapped transition to motherhood (e.g., *Breast$feed**) and qualitative methodology (e.g., *Interview**). Six databases were searched in April 2017 for peer-reviewed articles in English (Table 1).

Table 1: Systematic Search for Research on the Experience of Motherhood with IBD

	CINAHL	Cochrane Library	Ovid	ProQuest Health & Medicine	PubMed	Web of Science
Hits	106	19,728	1,316	187	271	8,735
Screened for English, peer-review, topic limit, duplicates	77	1,348	984	143	235	934
Selected by abstract and title scrutiny	20	0	45	11	19	27
Selected for full-text read	4	0	8	0	5	7
Selected from reference lists and 'cited in'	+1	0	+7	0	+1	+1
Removed duplicates across databases	-2	0	-1	0	-4	-3

Removed numerical content analysis	-1	0	-8	0	-2	0
Removed for not specifying illness	0	0	-3	0	0	-1
Not specific to mothers but family in general	-1	0	-1	0	0	0
Included and eligible n=7	1	0	2	0	0	4

Demonstrating a deficit of qualitative research in this area, only seven relevant articles were found. Only one of these focused entirely on the mother with IBD (Kimura & Ohmori, 2015) and the others included also the perspective of the woman's partner, relatives, and/or children. All were of acceptable rigor (Table 2), scoring at least seven out of ten (mean=8.57) on the 'Critical Appraisal Skill Programme' checklist designed to evaluate the quality of qualitative research (CASP, 2013). No date restriction was imposed and the articles ranged from 1970 to 2015; sample size from 1 to 30; data collection included one-to-one and group interviews; analytic methods included content, phenomenological, and framework analysis; four were conducted in the UK, and one each in Hong Kong, Japan, and the USA (Table 2).

A systematic review was conducted which involved generating clusters, themes, and subthemes integrating the main findings across all seven articles (Thomas & Harden, 2008). At the most parsimonious level, three clusters were identified: burden on family, coping, and conceptualization and integration (Table 2). Each article contributed to each cluster, although those which studied mothers, their significant other, and children produced the most detail (i.e., Kimura & Ohmori, 2015; Mukherjee, Sloper, & Lewin, 2002b; Mukherjee, Sloper, & Turnbull, 2002a). Three of the remaining articles were case studies of women with UC (Cooper, Collier, James, & Hawkey, 2011; Dudley-Brown, 1996; Liss & Sharma, 1970) and Lewis, Konda, and Rubin (2009) focused on genetic testing in the context of IBD.

Table 2: Qualitative Systematic Review: CASP Score, Study Details, and Clusters, Themes, and Subthemes

Author(s) Year	Liss and Sharma (1970)	Dudley-Brown (1996)	Mukherjee et al. (2002a)	Mukherjee et al. (2002b)	Lewis et al. (2009)	Cooper et al. (2011)	Kimura and Ohmori (2015)
CASP score	7	8	9	10	9	8	9
Participants relevant to systematic review	1 mother with UC	1 mother with UC	23 children	24 IBD parents	18 patients with CD, 11 with UC, 1 with IC	1 mother with UC	5 mothers with CD, 3 with UC
Data collection	Case-study interview	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews	Focus groups	Semi-structured interview	Semi-structured interviews
Data analysis	Implied Psycho-analytic	Phenomenological (coding memos)	Framework Analysis	Framework Analysis	Similarities & differences	Not specified	Content Analysis
Country	UK	Hong Kong	UK	UK	USA	UK	Japan
Clusters, Themes and Subthemes							
Burden on family							
Inability to fulfil mother role							
Caring, nurturing & feeding	✓	✓	✓	✓		✓	✓
Attending events		✓	✓	✓			✓
Fears & concerns							
Incontinence & drugs impact		✓		✓		✓	✓
Contaminating cycle of fear	✓		✓	✓	✓	✓	✓
Emotional load							
Guilt & shame		✓	✓	✓	✓	✓	✓
Feeling vulnerable	✓	✓	✓	✓	✓	✓	✓
Oscillating mood							
Coping							
Negotiating control							
Practical strategies	✓	✓	✓	✓			✓
Toilet & housebound		✓	✓	✓		✓	✓
Adjusting to new normality	✓	✓	✓	✓			✓
Adjustments to family life							
Close monitoring		✓	✓	✓	✓		✓
Protecting family interest	✓			✓	✓		✓
Maturation	✓		✓	✓			
Support & communication							

Need for support	✓	✓	✓	✓		✓	✓
Tighter bonds	✓		✓	✓			
Selective sharing		✓	✓	✓	✓		✓
Conceptualization & integration							
My IBD							
Origins	✓	✓	✓	✓	✓	✓	✓
Triggers	✓		✓				✓
Vivid awareness	✓	✓				✓	
Hidden illness							
Advocacy for validation		✓	✓			✓	
Disparity of knowledge	✓	✓	✓	✓	✓	✓	✓
Ambivalence towards medics	✓	✓	✓	✓	✓	✓	✓
Mums' needs							
Holistic approach		✓		✓	✓	✓	✓
Centralization of resources			✓	✓	✓	✓	

Burden on family. Maternal IBD places a burden on the whole family: symptoms impact the mother's ability to care for her children - such as cooking and cleaning - and flares in the early postpartum period can interrupt breast-feeding. For example, Mukherjee et al. (2002b) note that "(i)ncontinence and diarrhea meant it was a struggle for mothers to care for babies and preschool children (…) and being unable to leave the bathroom to attend to babies who were crying" (p.358). And urgency for toilet facilities made many aspects of life problematic, from the school run to attending events and going shopping. Shame over incontinence could confine the family to the house, while children could feel guilty if their mother's illness was exacerbated through family activities.

The hereditary aspects of IBD concerned mothers and IBD medication was a source of anxiety, as were hospital admissions due to flares. In fact, fear contaminated the whole family and could manifest through anger and attention-seeking behavior in children and, sometimes, the spouse. All studies reported that IBD made mothers feel vulnerable, e.g., through being physically, financially, and psychologically dependent on others, as Dudley-Brown's (1996) participant explained: "I couldn't go far (…) I just sort of walked around the bathroom while my husband took the kids" (p.62). Hospitalization meant that children were left with their father, grandmother, or even social services. Moreover, mothers often felt irritable and experienced mood swings due to IBD and its treatment, e.g., steroids, was linked to labile mood adding a burden on the family.

Coping. Participants developed ways of coping with the burden of IBD on the family. They struggled to reduce symptoms using practical strategies such as elimination diets and one of Kimura and Ohmori's participants had discovered that: "Oily or cold foods affect my abdominal condition, especially ice cream. So I don't eat it. I have dairy products with low fat" (2015, p. 42). In order to manage urgency, some even wrestled control by wearing adult diapers outside the house. Participants attempted to normalize family life

through humor and positive thinking, but the ever-present shadow of IBD meant that mothers monitored closely the bowel movements of their younger children. However, concerns were expressed about genetic testing, one of Lewis et al.'s participants saying that "it could create fear. Like everybody would worry if they [parents] find out they have the gene and then you're going to be like watching the kids" (2009, p. 498).

The genetics of IBD are complex and currently there is no test that can reliably predict the risk of developing IBD. Some attempted to cope by having just a small number of children and this could help mothers prioritize the needs of the family despite the burden of IBD. Children helped by doing chores and showed maturity by caring for their sick parent. Emotional support and help with tasks was also provided by extended family, friends, neighbors, and spouse – as one explains: "I always have to bear in mind that I have to be a bit, sweeter to her and try not to do silly things or get involved in stupid arguments" (Liss & Sharma, 1970, p. 470). Coping with maternal IBD could tighten family bonds and children recalled spending quality time at home. However, information about the illness tended to be shared with only few trusted friends.

Conceptualization and integration. Most women had the understanding that their illness was a combination of environmental and genetic factors and children appreciated the remitting-relapsing nature of IBD, conceptualizing it on a continuum of wellness. One child said: "I think it's quite serious, well not life-threatening, but serious (…) it's serious in the sense that it's basically permanent, it's not as serious as something like cancer, but it's quite serious' (Mukherjee et al., 2002, p. 481). Participants identified triggers that could exacerbate symptoms, such as stress or specific foods, and most had a vivid recollection of the onset, duration, and timespan between flares. IBD was considered a hidden illness and participants had to advocate for the validity of their symptoms, often relieved to receive a diagnosis as proof of their condition. Cooper et al.'s participant explained: "I kept saying to

them [medical staff], ‘please listen to me, it’s not the baby, the blood’s coming from my bottom’. They were saying, ‘well you know you might be getting confused’. I felt like nobody wanted to know and I was so traumatized” (2011, p. 31).

All studies reported how the hidden nature of IBD meant a lack of knowledge amongst the public, but also amongst general medical staff, and relationships with health providers was influenced by their empathy and awareness of the illness. Most mothers had found it difficult to get information about pregnancy and IBD and wanted greater centralization of resources allowing a more holistic approach to care during prenatal and postpartum years with the medical team considering also the needs of the family. Having established the deficit of research in this area, and the cohering themes of the work available, this study set out to address the research question: What is the experience of transition to motherhood with IBD?

Method

Ethics

The study received ethical approval from the University of Leeds, UK (ref 14-0280).

Participants

The study was advertised via Crohn’s & Colitis UK, relevant websites, and social media from September 2014 until August 2016. Inclusion criteria were a self-reported medical diagnosis of IBD, 18< years old, and having at least one child (to whom she gave birth) aged between about 2 and 7 years. Of 98 inquiries, 22 women were selected from across UK. We sought a balance of participants with CD and UC and employed first convenience and then purposive sampling to maximize diversity of geographical location and experience (e.g., having an external pouch or ‘stoma’). Finally, as analysis proceeded, participants were recruited for specific characteristics (e.g., single mother) on the basis of theoretical

sampling to close gaps in understanding. The sample meets Patton (2002) definition of a large qualitative study (see Supplemental File).

Data Collection

A semi-structured interview schedule was created and refined through piloting. It comprised 23 questions designed to tap into the experience of transition to motherhood with IBD. It covered IBD diagnosis, planning, conception, pregnancy, and the early years of motherhood. An information sheet was provided and multiple opportunities given for participants to ask questions about the study before signing the informed consent form. Key information was gathered from each participant via a short questionnaire at time of recruitment from which a personalized timeline was created. Interviews were conducted by Ghorayeb and audio-recorded at the participants' home, except two which were conducted over Skype (mean=71mins, range=39-113). Interviews were transcribed orthographically with the following conventions: (.) short pause; (3) longer pause in seconds; ((laugh)) paralinguistic information; […] omitted text; [daughter's name] for anonymization; [her] for contextual clarification.

Data Analysis

Transcripts were analyzed using thematic analysis (TA: Braun and Clarke (2006). In terms of specifying the type of TA conducted: a *critical realist* stance s taken (Maxwell, 2012), meaning that, while knowledge is considered partial and culturally-situated, it is accepted that physical bodies and social structures exist and have real impacts; the analysis constitutes a *rich description* in that it draws from across the entire data corpus; themes were derived *inductively*, that is 'bottom-up'; and involve predominantly *semantic* themes (in which meanings are derived directly from the participants' own words) with a smaller number of *latent* themes (in which meanings are derived more indirectly via researcher interpretation).

The six phases described by Braun and Clarke guided the analytic process: familiarization with the data, generating initial coding, searching for themes, reviewing themes, defining and naming themes, and reporting. Transcripts were checked against audio-recordings for accuracy, read carefully several times, and initial notes and potential codes discussed between the Ghorayeb and Madill. Ghorayeb kept a reflexive diary, taking notes before and after every interview. Note keeping allowed her to examine more closely the assumptions and subjectivity added to the analysis. Intersubjective reflection showcase how the authors' position as a researcher influenced the decisions made and the analysis generated (Finlay, 2002). Themes, and more detailed sub-themes, were identified, provided tentative labels, and plotted in word documents and excel sheets. These were reviewed several times and adapted to fit better the data through an iterative process of close examination of the transcripts, comparison between participants, and considering the entire data corpus. A small number of key concepts were identified around which many themes and subthemes clustered, one of which is selected for presentation in this article: that of '*Blurred Lines'*.

The study includes two different kinds of member check. First, Madill is also a mother with IBD so she provided member checking through undertaking a pilot interview and utilizing her own experiences to deepen Ghorayeb's approach to the study and probe her developing understandings. Ghorayeb provided a productive counter-balance as a women not diagnosed with IBD, not yet a mother, yet highly familiar with the detail of the interviews. This meant that she was able to ask creatively open questions of the data and contextualize the lead supervisor's personal experience within a wider picture supported by the keeping of a reflexive research diary. Second, the analysis is informed by feedback from people with IBD and their family provided after presentations at Crohn's & Colitis UK forums. These individuals were attending the meetings and were not taking part in the

research. They reported that the results felt relevant to their own experience of becoming a mother (when applicable), and for those thinking about motherhood they said the results were encouraging. Expert checks were provided during the iterative development of the analysis from the two academic supervisors but also from Selinger who is a Consultant Gastroenterologist with particular expertise in IBD and pregnancy.

Results

The analysis first captured similarities between changes in dietary habits of women with IBD as well as the changes made by women who were pregnant. A closer look at other areas of similarities in the experience of motherhood and having IBD led to the delineation of the concept of *Blurred Lines*. *Blurred Lines* captures the parallels participants experienced between having IBD and of becoming, and being, a mother. *Blurred Lines* consists of three themes, each contributed to by all 22 participants: *Need for Readiness*, *Lifestyle Changes*, and *Monitoring Personal and Physical Development*. Each theme has four more detailed subthemes (Table 3). The following analysis explicates each theme, providing evidence in the form of quotes from the participants, while taking care to maintain the uniqueness of each woman and to consider experiences which appear to challenge or complicate aspects of the analysis. Participant quotes are identified as being from a women with Crohn's Disease (CD), ulcerative colitis (UC), or IBD undifferentiated (IBDu) followed by her number of children (e.g., CD2).

Table 3: Themes and Subthemes of 'Blurred Lines'

Themes	Subthemes	Contribution (total n=22)
Need for Readiness	Need for maturity	20
	Identifying blame	22
	Fear of mortality	20
	Seeking others' experience	22
Lifestyle Changes	Regime alterations	21
	Libido loss, sleeplessness & fatigue	22
	Dependence	20

	Adapting to change	22
Monitoring Personal & Physical Development	Weight change	17
	Symptom confusion	21
	Seeking respite	21
	Identity change	22

Need for Readiness

Many felt that, given their relative youth, they should not have to be ready to cope with a serious illness and one, who was diagnosed as a teenager, regretted that IBD had "made [her] grow up too quickly" (CD2). Similarly, participants perceived motherhood to require a developed sense of maturity. Some felt prepared: "I was ready to become a mum (.) so I felt mature enough to (.) to handle the challenges" (UC1), but this was very individual and not associated with age, given that both younger and 'older' mothers discussed varying degrees of subjective readiness.

IBD was blamed for putting one at a disadvantage in terms of being ready to meet the normal challenges of life, including the expectation of becoming a mother. For example, describing the impact of the painful symptoms of IBD, one participant feared that: "I wasn't being the mum that I should" (CD2). Two women had the unusual experience of receiving their diagnosis whilst pregnant and blamed it for triggering IBD. And one even considered termination because she was struggling to cope with the illness, saying: "if someone had told me that at the beginning before I got pregnant that I would have had a really bad pregnancy like that I wouldn't have got pregnant" (UC2).

In fact, both IBD and motherhood raised many anxieties about mortality. IBD can be severe and one participant, who had her bowel removed in her early twenties, recounted how she "wouldn't be here" (CD2) had she not received a stoma. In addition, the specter of one's own death can be particularly frightening for a mother because "when you've got a child you start thinking I've got to be there for them at least for a certain point" (UC1). Other participants also had to be ready to face the precariousness of new life and one

described how “being five weeks post-surgery, I didn’t know whether it would be possible to continue my pregnancy” (CD2). For two women, screening suggested high risk of Down Syndrome but both declined termination after being offered the choice. Another, who lives in Northern Ireland, also explained that she would want to keep her baby - whatever the risks - regardless that local laws proscribe termination.

The women tried to ready themselves for the impact of IBD by attending support groups, consulting medical staff, joining online forums, and talking with friends who have a chronic illness. Similarly, regarding pregnancy and motherhood, they had recourse to their mother or mother-in-law, gynecologist, friends who were already parents, and did their own reading. However, participants concluded that most general practitioners, midwives, and nurses knew little about pregnancy with IBD and one recalled how she “went to the midwives and they were like ‘Oh (.) I don’t know’ um (.) So they printed off (.) they looked it up and printed off some information and gave me it’” (UC1).

Lifestyle Changes

Everyday regimes pertinent to both IBD and pregnancy include diet, routine activities, and leisure pursuits. In pregnancy, participants referred to their adapted diet in terms of healthy eating, and those who were diagnosed with IBD before their pregnancy(ies) seemed ‘ahead of the curve’ having already made healthy lifestyle choices because of their illness. For one, pregnancy even increased her food choices because, with reduced toilet urgency, she said “I could eat what I wanted (.) I could eat fruit again which was nice” (CD2). A particularly interesting parallel described by participants was that some beverages counter-indicated in pregnancy, such as alcohol and caffeine, were best avoided also in IBD due to their exacerbation of symptoms. However, smoking may be a counter example in that one mum mentioned that “whilst I did smoke I never used to have any of the symptoms” (IBDu1) and since quitting in an attempt to get pregnant, her symptoms had worsened.

Sexual intimacy tended to reduce when women experienced a flare, and this was echoed during the first years of motherhood. Interestingly, one participant could reflect on the additional impact of IBD given that her illness had developed between pregnancies: "intimacy came back quicker after having [First Daughter Name], the first, and having [Second Daughter Name] and being diagnosed with UC" (UC2). Reduction in sexual activity could be related to tiredness. Fatigue is a symptom of IBD, moreover toilet urgency can be taxing, and sleep disturbance is common in pregnancy and while caring for a baby. In fact, one participant explained that, for her, the most difficult aspect was fatigue: "I can't afford to be tired on top of already being tired (.) you can't function really and work" (UC1). It was difficult to know if fatigue was a normal aspect of pregnancy and motherhood, or if it was IBD-related and needed treatment, and this ambiguity caused participants much anxiety.

Having IBD, or being a mother, can place a woman in a state of dependency on others financially, emotionally, and in everyday tasks. Only one participant talked at length about the financial implications of dealing with IBD whilst she was a student and the devastating impact on her savings (UC2), but most reported briefly how having children and/or IBD is expensive for a couple. Impacts include returning to work, breast- rather than bottle-feeding, finding free family activities, and limiting unpaid leave. One participant (UC2), with over 10 years of IVF, said that it was because of her Jewish community that she and her husband had been able to afford the treatment that had provided them twins. Participants diagnosed at a young age (<18 years) mentioned relying on their parents for support. Similarly, in pregnancy, participants tended to rely on their mother and partner, and were particularly dependent on this support if they had a Caesarean-section, breast-fed, or experienced IBD flare or surgery with young children. Moreover, the mother's dependence on toilet facilities meant that outings needed a lot of planning and one

explained that “I’m always scanning somewhere (.) ‘Oh there’s a McDonald’s there (.) oh there’s a café there (.) oh yeah (.) you know (.) so if I need to go in an instant I know where I could run” (UC2). On the other hand, becoming a mother revealed how dependent her child was on her and reinforced the need to stay well: “It’s such a big responsibility to have a child you know that relies solely upon you for absolutely everything” (CD2).

Being a mother with IBD entailed adapting to changes between looking after her own health and making sure she met the needs of her children. These responsibilities are not mutually exclusive but a new consideration was that you’ve “got somebody else to look after […] you’re responsive to everything that happens to that little boy” (IBDu1). As mums the participants worried if their children were safe, properly fed, and cared for. In addition, as mums with IBD, they worried about having passed-on the illness: “He’s got to four (.) he hasn’t had it yet (.) let’s hope that he doesn’t” (CD1). However, dealing with the unpredictability of IBD was good practice for the ever-changing schedules and challenges of motherhood: “greater preparedness for things not going to plan because I do think that’s one of the big hurdles in coming to accept that you’ve (.) accept your illness is that you’re not you’ve not got ultimate control over your life” (CD1).

Monitoring Personal and Physical Development

Weight change is characteristic of IBD given chronic diarrhea and the effect of medication. Weight change is also an inherent aspect of pregnancy. A few who had IBD as teenagers initially were thought to have an eating disorder due to severe weight fluctuation and one explained how she “dropped um (.) to about five stone and became very gaunt” (CD1). In contrast, weight gain reflected periods of remission and, in pregnancy, positive fetal growth. However, there was an upper limit to the women’s perception of positive weight gain and one said that “another challenge would be that I'd been used to being of sort of fairly slim build, but there was no guarantee I'd go back to that after the pregnancy” (UC1).

Similarly, participants who took steroids to reduce inflammation feared the side-effect of weight gain, particularly in their teenage years: "I would just cry my eyes out (.) going please (.) anything but steroids because I'd worked so hard after I gained the weight to go to exercise classes (.) do diets (.) everything to try and lose it" (UC2).

Both pregnancy and IBD affect the abdominal and pelvic regions. This can make it difficult to identify if symptoms are illness or gestation/labor-related and one participant thought she was having a flare when she was in labor because "the labor pains [and] the Crohn's pains […] they are so similar and so intense" (CD1). Diarrhea or losing blood in stools was often attributed to pregnancy hemorrhoids: "my doctor said 'Oh it's piles, piles. You get it when you're pregnant'" (UC2), but participants feared these actually preluded a flare. Symptom confusion also included back, joint, abdominal and pelvic pain, sickness, sleeplessness, fatigue, and lack of libido. This could make the combined experience of IBD and motherhood much harder and one explained how "I had swellings on my legs which they said was erythema nodosum I think they called it (.) but it was like an arthritic type thing but it was an effect of the Crohn's Disease" (CD2). Lastly, some participants drew attention to the parallels between the scar of a Caesarean-section and that of a bowel operation, but "joked that it would be like noughts and crosses ((laugh)) on my stomach" (CD2).

For some, pregnancy was linked with flares and they were reticent to have more children, fearing also that they would not cope with a second or third child while ill: "you're sort of associating it [pregnancy] with the fact that you're gonna have a flare-up so it's definitely put us off having any more" (UC2). In fact, participants sought respite from both the symptoms of their illness and from the exhaustion of caring for their children. However, for some, respite from IBD could come in the form of pregnancy and one

described how she kept her two pregnancies closely successive since gestation kept her symptoms at bay.

Having IBD, and becoming a mother, both had a huge impact on the participants' sense of identity. Some described how IBD had a negative impact on their personality and how they socialize: "going out with friends is hard because um (.) I can't really just sit down and look at the menu and choose something that I want to eat in a restaurant because I know that the next day I'll be suffering" (UC2). Others perceived a more positive influence, for example in that "it sort of shaped how I approach things and my mind-set (.) and I think I'm a stronger person for having Crohn's" (CD1). While ultimately optimistic, one explained how motherhood had taken a toll on her sense of self "it's definitely made me feel old but it's been the best thing" (UC1). More generally, participants described becoming known as their 'child's mummy' and, maybe more profoundly, developing a strong sense of responsibility and purpose. And, having gone through often immense physical suffering related to their IBD, motherhood could restore to women the amazingly positive identity that it was the self-same body which had produced "a beautiful little creature" (CD1).

Discussion

The analysis offers a novel frame for understanding the transition to motherhood with IBD through identifying parallels between having IBD and becoming, and being, a mother. Specifically, *Blurred Lines* exist between the way that both IBD and motherhood are experienced as demanding a *Need for Readiness*, *Lifestyle Changes*, and *Monitoring Personal and Physical Development*. It is encouraging to discover that women with IBD are in some ways well prepared for the challenges of motherhood even though, as a group, they tend to restrict their reproductive choices.

The first theme, *Need for Readiness,* captures how mothers with IBD considered both motherhood and IBD to involve a *need for maturity*. Participants had their first child at 31 years, on average. Shelton and Johnson (2006) found that, while women who became mothers for the first time in their 30's often felt ready for this life transition, they were not always realistic about the challenges involved. Practical implications aside, having a baby, perhaps paradoxically, can underscore the fragility of life (Taubman-Ben-Ari & Katz-Ben-Ami, 2008). And *fear of mortality* could be magnified for mothers with chronic conditions who may be anticipating further decline in health - even if this fear does contrast medically-reported mortality in the case of IBD (Card, Hubbard, & Logan, 2003).

A diagnosis of IBD, or news that one is pregnant, can be accompanied by a need to *identify blame*. Even in the best circumstances, women can feel under intense scrutiny and vulnerable to being blamed for not doing the best for her baby (Sheehan, Schmied, & Barclay, 2010), which may include criticism for becoming a mother with a chronic illness. On the other hand, overlaps between the signs of pregnancy and symptoms IBD can make it difficult to diagnose the illness, or a flare, and so women can form time-sensitive links between their pregnancy and deterioration in health (Cooper et al., 2011). Feeling accountable, but also in need of information, participants were *seeking others' experience* and reaching out via the Internet to mums' and/or IBD groups and forums. The Internet is a source of support for many people and, according to Kim and Lee (2014), use of cyber-based portals is associated with good chronic illness management.

The theme *Need of Readiness* triangulates well with the systematic review (see Introduction). The existing research identifies how children can develop strategies beyond their years to cope with their mother's IBD. Similarly, this study documents how women perceive a *need for maturity* from themselves, also, as they embark on the journey to motherhood. In relation to *identifying blame*, this study substantiates further the guilt

experienced by mothers with IBD for its perceived negative impact on their family. And in *seeking others' experience* this study confirms the need these mothers have for support and advice. However, a novel aspect of the study is identification of how transition to motherhood with IBD raised for many a palpable *fear of mortality*.

The second theme, *Lifestyle Changes,* reflects how both IBD and transition to motherhood implicate *regime alterations*. For example, Langmead and Rampton's (2006) review of the use of Complementary and Alternative Medicine (CAM) placed IBD sufferers amongst the most engaged. Similarly, during pregnancy many women turn to CAM for relaxation and to avoid medicines that could impact their baby (Warriner, Bryan, & Brown, 2014). However, this is potentially a dangerous approach to healthcare because tight IBD symptom control during pregnancy is important for both the mother's and the baby's health (Van der Woude et al., 2015). In terms of diet, Palant et al. (2015) found that women with IBD could feel uncertain about what to eat and, as a result, restrict their intake. Diet recommendations during pregnancy can also be confusing and many women experience changes in appetite (Bayley, Dye, Jones, DeBono, & Hill, 2002; Bowen, 1992). Interestingly, one participants described being protected from IBDu symptoms whilst smoking before her pregnancy. Parkes, Whelan, and Lindsay (2014) report that smokers with UC tend to have a less severe disease course. Hence, while smoking would never be recommended, this example highlights the complex interactions between behaviors and health as women negotiate a pregnancy on top of chronic illness.

Other *Lifestyle Changes* relevant to IBD and transition motherhood were *loss of libido, sleeplessness and fatigue*. Disturbed sleep is a fact of early motherhood, but those with IBD may also have to visit the toilet frequently during the night. One impact is less energy for physical intimacy with one's partner and Timmer et al. (2008) report that IBD can be associated with sexual dissatisfaction due to psychosocial factors, particularly

depression. Participants also experienced emotional, practical and financial *dependence*, especially during a flare or when children are young. Similarly, Mitchell and Green (2002) found that first-time mums relied on family, particularly their mother, when adapting to their new role. Hence, both transition to motherhood, and living with a chronic illness require *adapting to change* but, happily, all the *Lifestyle Changes* documented in the study had some positive impacts and may be good preparation for the demands of motherhood, such as developing a flexible schedule.

The second theme - *Lifestyle Changes* – builds on the extant research outlined in the qualitative systematic review. Specifically, this study adds detail with regard to the *regime alterations* required to cope with IBD and motherhood through, for example changes in diet; the *dependence* and vulnerability women can experience financially, emotionally, and physically; and their concerns about *adapting to change* in their transition to motherhood. However, a particular development this study offers is with regard to specific challenges such as *libido loss, sleeplessness and fatigue*.

The third theme, *Monitoring Personal and Physical Development*, captures the way in which both transition to motherhood and having IBD can involve intense self-scrutiny. One shared focus is *weight change.* Appropriately increasing weight is usually a sign of good health in both pregnancy and IBD (DeVader, Neeley, Myles, & Leet, 2007). Conversely, having active disease at the time of conception or during pregnancy, restricted diet, or compromised digestion can lower gestational weight associated with low baby birth weight and admission to neonatal intensive care (Oron et al., 2012). However, some participants feared excessive weight gain associated with steroid medication alongside the concern, many women have, of losing their pre-pregnancy figure. A complexity for the participants was *symptom confusion* in that it could be difficult to attribute phenomena to normal, or problematic, aspects of one's pregnancy or to IBD. It may be particularly

difficult to negotiate personal and professional knowledges within the context of pregnancy with chronic illness (Tyer-Viola and Lopez (2014). In such circumstances, evidence-based reassurance, or diagnosis and appropriate treatment, could be delayed and pregnant women with chronic illness left feeling undermined and vulnerable.

Being pregnant and looking after small children can be exhausting. If one also has a chronic illness, particularly like IBD in which fatigue is a symptom, *seeking respite* is an important consideration. In this respect, participants had to make, sometimes hard, decisions about the number of children with which they could cope (Kwan & Mahadevan, 2010). They also described coping with *identity change* which incorporated loss, such as no-longer being a 'healthy person', but also the almost ubiquitous experience of losing elements of individuality in becoming 'a mother'. However, they were also positive that having IBD contributed to their resilience and ability to be grateful for their child(ren). As Hoppe (2013) report, individuals with chronic illness not only find happiness in spite of their illness, but through the illness as well, for example in bringing them closer to friends and loved ones.

The theme, *Monitoring Personal and Physical Development*, builds on the existing research reported in the systematic review. Mothers are highly vigilant of their own and their children's physicality and this is captured in our study in terms of *weight change*. The current study also substantiates the possibility of *symptom confusion* between IBD and pregnancy. However, novel aspects of the study are the difficult decisions often required in the process of *seeking respite* from the challenges of motherhood with IBD and the ways in which mums may experience a complex constellation of *identity change*, often associated with loss.

Limitations

Although an effort was made to recruit participants who could provide information about diverse experiences of transition to motherhood with IBD, it is possible that women with very severe illness were under-recruited because they did not feel well enough to volunteer. We would also like to have interviewed more single mothers but, despite a specific call, it was difficult to recruit this demographic. Similarly, we would like to have included women with more than two children and, although we did interview one with three children, heartbreakingly audio-recording failed. Finally, the sample may underrepresent the challenges faced by less economically-privileged women. It was considered unethical to pursue women who stopped responding to follow-ups, so have no information on why individuals dropped-out after expressing initial interest. However, we are pleased to have recruited a sample that is diverse in many ways (i.e., type of IBD, geographic location, time of IBD onset), can demonstrate excellent contribution across the sample to each theme of the analysis, and have been careful to describe where individuals had experience or opinions which were different or unique.

Audulv, Asplund, and Norbergh (2012) used a longitudinal qualitative research and indicated how some of the individuals suffering from chronic illness integrated self-management techniques overtime (2.5 years). We, on the other hand, only interviewed mother with IBD on one occasion, but we selected some who were currently pregnant, others planning for a second child, and some who already had their desired number of children to overcome this pitfall and give a breadth view of the changes that occur as women with IBD transition from a nulliparous life to motherhood. Moreover, the use of Skype interviews to complement face-to-face interviews allowed us to overcome geographical barriers and interview women with IBD who lived remotely. The use of Skype also allowed women who experienced IBD symptoms at the time of the interview to remain in the comfort and safety of their home. They could easily reschedule or take breaks

and not have to worry about having an interviewer present in their home. Skype however poses some limitations with regards to bodily cues and possibly establishing rapport (Lo Iacono, Symonds, & Brown, 2016). In our research, we did not find it more difficult to establish rapport but the technical cuts and interruption due to internet connection loss did halt the flow of the conversation. The two participants who were interviewed gave verbal consent to be video-recorded which allowed Jihane Ghorayeb to analyze the transcript whilst looking at the video and picking up facial expressions.

Conclusion

Many women with IBD are childless due merely to lack of information and are assuming – usually incorrectly – that pregnancy would be medically dangerous and parenting just too challenging to face on top of their illness (Selinger et al., 2013). This study confirms that they are hungry for information about the impact of IBD on reproduction and it is recommended that health professionals *initiate* this conversation, do so *early,* and provide an opening for discussions about maintaining sexual intimacy with their partner in the early years of motherhood (Borum, Igiehon, & Shafa, 2010). This study also identifies issues for health professionals to be alert with regard to motherhood and IBD. These include increased anxiety with regard to women's own health and life-expectancy - and that of her baby - and use of self-prescribed diets and other interventions. Finally, there is a need for a more holistic, multidisciplinary approach to pregnancy and IBD – and probably other chronic illness – which better integrates on-going treatment with women's maternity care.

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Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

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Supplemental Material

Supplemental material is available consisting of a detailed table of participant characteristics.

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Supplemental File: Participant Characteristics

Participant Characteristics (n=22)

Characteristics		Frequency	Percentage	Mean	Range
IBD type	Crohn's Disease	11	50.0	-	-
	Ulcerative Colitis	10	45.5	-	-
	IBD undetermined	1	4.5	-	-
Age at interview		-	-	35.82yrs	29 - 42yrs
Age at diagnosis		-	-	23.77yrs	10 - 41yrs
Years with IBD		-	-	12.09yrs	1 - 25yrs
Number of children:	One	10	45.5	-	-
	Two	12	54.5	-	-
Age first-born		-	-	4.24yrs	10mnths - 8yrs
Time diagnosis to 1st-born		-	-	7.55yrs	-6 - 22yrs
Time diagnosis relative to pregnancy					
	Before pregnancy(ies)	15	68.2	-	-
	During 1st pregnancy	2	9.1	-	-
	Between pregnancies	1	4.5	-	-
	During 2nd pregnancy	2	9.1	-	-
	After pregnancy(ies)	2	9.1	-	-
Ethnicity	American British	1	4.5	-	-
	Caribbean British	1	4.5	-	-
	French British	1	4.5	-	-
	Guyanese British	1	4.5	-	-
	Indian British	1	4.5	-	-
	Jewish British	1	4.5	-	-
	Other White British	16	72.7	-	-
Marital status	Divorced	1	4.5	-	-
	Married	21	95.5	-	-
Education level	Secondary school	1	4.5	-	-
	Apprenticeship	8	36.4	-	-
	Bachelor	11	50.0	-	-
	Master/ PhD	2	9.1	-	-
Work status	Full-time	5	22.7	-	-
	Part-time	13	59.1	-	-
	Homemaker	4	18.2	-	-
Household income	45,000<	12	54.5	-	-
	30,000<45,000	5	22.7	-	-
	15,000<30,000	2	9.1	-	-
	Missing (Low inferred)	3	13.6	-	-
Type of treatment	Counselling	6	24.5	-	-
	Dietary	15	68.2	-	-
	Medication	22	100.0	-	-
	Medication in pregnancy	15	68.2	-	-
	Surgery	7	31.8	-	-